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REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

HEARING

BEFORE THE

SUBCOMMITTEE ON DISABILITY POLICY

OF THE

COMMITTEE ON
LABOR AND HUMAN RESOURCES
UNITED STATES SENATE

ONE HUNDRED FIRST CONGRESS

SECOND SESSION

ON

EXAMINING PROPOSED LEGISLATION AUTHORIZING FUNDS FOR PROGRAMS OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

MARCH 30, 1990

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CONTENTS

STATEMENTS

FRIDAY, MARCH 30, 1990

Page
McFadden, Deborah L., Commissioner, Administration on Developmental Disabilities, U.S. Department of Health and Human Services 4
  Prepared statement 7
Boggs, Dr. Elizabeth M., Ph.D., Hampton, NJ, on behalf of the Consortium for Citizens With Disabilities; Dr. K. Charlie Lakin, research director, Institute on Community Integration, University of Minnesota; and Helen Coburn Roth, Logan, UT 48
  Prepared statements of:
    Dr. Boggs 51
    Dr. Lakin 75
    Ms. Roth 87
Campbell, Ken, executive director, Ohio Developmental Disabilities Planning Council, on behalf of the National Association of Developmental Disabilities Planning Council; F. Henry Brown, Greenville, SC, on behalf of the National Association of Protection and Advocacy Systems; Dr. Alfred Healy, director, Iowa University Affiliated Program, Iowa City, IA, on on behalf of the American Association of University Affiliated Programs; and Kim Hurley, University of Northern Iowa, on behalf of University Affiliated Program 99
  Prepared statements of:
    Mr. Campbell 103
    Mr. Brown 129
    Dr. Healy 139
United Cerebral Palsy Associations, Inc., Allan I. Bergman, on behalf of, prepared statement 151

REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ASSISTANCE AND BILL OF RIGHTS ACT

FRIDAY, MARCH 30, 1990

U.S. Senate,
Subcommittee on Disability Policy,
of the Committee on Labor and Human Resources,
Washington, DC.

The subcommittee met, pursuant to notice, at 9:38 a.m., in room SD-430, Dirksen Senate Office Building, Senator Tom Harkin (chairman of the subcommittee) presiding.

Present: Senators Harkin, Thurmond, and Durenberger.

Opening Statement of Senator Harkin

Senator Harkin. The subcommittee will come to order.

The Subcommittee on Disability Policy is meeting today to review programs authorized under the Developmental Disabilities Assistance and Bill of Rights Act, which expires at the end of this fiscal year.

There are four components to this Act: the Basic State Grant, the Protection and Advocacy Systems; University Affiliated Programs, and Projects of National Significance.

The Basic State Grant Program provides payments to State Developmental Disabilities Planning Councils. These Councils advocate for and assist in developing a comprehensive system of services for persons with developmental disabilities.

The Protection and Advocacy System protects the legal and human rights of persons with developmental disabilities through legal, administrative, and other appropriate remedies or approaches.

The University Affiliated Programs conduct interdisciplinary training, demonstrate exemplary services and technical assistance, and disseminate information which will increase and support the independence, productivity and integration in the community of persons with developmental disabilities.

Projects of National Significance are conducted in order to increase and support independence, productivity and integration.

The four components of the Act are funded at a combined level of $96.477 million this year.

Since the last authorization, a number of things have happened. This hearing has a special significance to me, since my first bill as chairman of the Subcommittee on Disability Policy was the reauthorization of the DD Act in 1987.

The programs authorized under this Act could be considered small in the general scheme of things, but they are small programs that make a big difference. These are capacity building programs. That means they build upon the network of services for people with developmental disabilities across the country by promoting awareness and coordination, setting new directions, training the new generation of professionals who will work in these programs, and ensuring the rights of all citizens with disabilities to live a life of independence and dignity.

An important provision in the 1987 Amendments to the Act was a mandate for each State Planning Council to conduct a comprehensive review and analysis of services provided by all State agencies with responsibilities which affect the lives of people with developmental disabilities. Further, we called for a review and analysis of the effectiveness of Federal and State developmental disabilities functions and services from the consumer's point of view. Public forums were conducted in each State and Territory during which people with disabilities, their families, interested citizens and service providers offered testimony.

On January 1, 1990, the 56 State and Territorial Developmental Disabilities Planning Councils presented the results of these reports, called "The 1990 Reports", to their governors and legislatures. An aggregation of these State and Territorial reports will be presented by the Secretary of Health and Human Services to members of Congress.

This bold step forward will provide a blueprint for the improvement of public policies which affect people with disabilities. So this is an exciting and unprecedented opportunity for progress, and one that we must take full advantage of.

We have several witnesses with us today who will talk about what we have accomplished under this Act and suggest to us what new directions, modifications or changes they would like us to consider, and I look forward to hearing from our witnesses.

Before I call the first witness up, I would like to recognize the distinguished ranking member of this subcommittee, an individual who has a long record of support, compassionate and caring for developmental disabilities programs and all of the programs under the purview of the Subcommittee on Disability Policy, my colleague from Minnesota, Senator Durenberger.

OPENING STATEMENT OF SENATOR DURENBERGER

Senator **DURENBERGER**. Thank you, Mr. Chairman.

As we head into the last decade of the 20th Century, we are going to face some very critical decisions about how we deal with the problems facing people with developmental disabilities.

I am fortunate to have a view not only from where I sit today on the Subcommittee on disability Policy, but also as a member of the Senate Finance Committee—and particularly as the Ranking Member of the subcommittee which has jurisdiction over Medicare and Medicaid. I have been watching with some frustration over the years, especially since 1985 when we began doing public policy through deficit policy, the frustration in trying to make policy for dealing with the problems of the developmentally disabled or taking advantage of the opportunities that exist.

It is clear to me that there is a wide gap between what we know to be possible and desirable in the area of developmental disabilities and what is currently supported most appropriately by Federal as opposed to State or local policy. And I am hopeful that this reauthorization process will allow this subcommittee and the full committee to review our current knowledge as well as current practices and see where those gaps are and what we ought most appropriately to recommend to our colleagues to change and improve conditions for persons with developmental disabilities.

The foundation for the services and the support for persons with developmental disabilities is in place. The engine that makes the system work has come in the power that this bill has given to individuals and to their parents.

Where we need to go from here is ensuring that those who are eligible are aware of the services, to ensure that there are trained people available to meet the demand.

Another issue that I feel fairly strongly about is that in my own State of Minnesota, there are somewhere between 43,070 and 103,368 people with developmental disabilities; at the national level, there are somewhere between 1.7 million and 4.7 million. There is no current method to determine the exact figures. This is crazy, that we have this kind of wide variance in our estimates.

Dealing with the realities and the actualities I think is a major responsibility for Federal policy. We don't have in place a system that can accurately measure the number of people who meet the definition of developmental disability, and I hope that during the reauthorization process, we are going to look for ways to accurately measure who those people are and where they are, so that we can best suit the policy to their needs.

I would hope that the passage of the Americans with Disabilities Act later this year will also place additional strains on programs under this Act—and I say I hope it does, because I want to see that bill passed very much. I know that it will put strains on the programs under this Act, and I trust, working with the chairman, who designed that Act, that this reauthorization process will also be able to anticipate how the provisions in this bill can be modified to ensure the smooth implementation of the ADA.

And finally, Mr. Chairman, I would like to welcome Debby McFadden here today in her first official appearance before this subcommittee since becoming Commissioner of the Administration on Developmental Disabilities.

I also want to welcome also our friend Charlie Lakin, from the University of Minnesota—actually, from Iowa and now at the University of Minnesota. I have said facetiously, and this always a rejoinder, but you have to get out of Iowa to amount to something. That is certainly not true of its politicians.

Charlie is himself a foster parent of a young woman with developmental disabilities and besides that has become nationally known for his research regarding community and residential services for people with mental retardation and developmental disabilities. I consider myself fortunate to have such a distinguished scholar and advocate for the rights of people with developmental disabilities in my State and as my resource and our resource to this subcommittee.

Senator **Harkin**. Are you ready for the rejoinder? [Laughter.]

Senator **Durenberger**. Out of the "Iowa/Minnesota Joke Book", right?

Senator **Harkin**. Fortunately, we always have to educate them before we send them to Minnesota, right? [Laughter.]

It never ends.

I, too, want to welcome Deborah McFadden, Commissioner of the Administration on Developmental Disabilities in the Department of Health and Human Services.

Welcome. This is your first appearance before this subcommittee, and please proceed with your testimony. For you and for all of the witnesses, your statements will be made a part of the record.

What I would really appreciate, as I always tell witnesses, what are the three or four things that you think we really ought to know, or you really want to focus on, and highlight those for us, and then we can get into the question-and-answer period.

STATEMENT OF DEBORAH L. MCFADDEN, COMMISSIONER, ADMINISTRATION ON DEVELOPMENTAL DISABILITIES, U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES

Ms. **McFadden**. I am very pleased to be here and to appear before this subcommittee.

I do want to submit for the record some of the nuts and bolts of our program, but I do want to tell you my viewpoint on the heart and soul of the Administration on Developmental Disabilities.

In a lot of ways I feel somewhat like Christopher Columbus—he knew the Earth was round, insisted on proving it, and wound up discovering a whole new world. As ADD Commissioner, I know that life can be better for people with developmental disabilities, and I insist on proving it. And who knows? Perhaps our efforts will in fact lead to a whole new world for those with disabilities.

Of course, Columbus didn't discover anything alone, and neither can I. He had captains and crews of each of his ships, making sure they kept on course. I am fortunate enough to have terrific, talented people making sure each of our programs stays on course—the State Planning Councils, the Protection and Advocacy Agencies, the University Affiliated Programs, the Projects of National Significance, and of course, my own crew, my staff.

In its role as leader of this expedition, ADD gives direction, promotes communication, and strengthens coordination among our three ships—the DD Councils, the P&A's, the UAP's—so we can sail ahead together toward our goal of full integration into society.

Columbus did get what he was after—and a lot more. Why? Because his fleet worked together and never lost sight of its purpose. We at ADD want to do the same thing.

I know you are all familiar with this, but for the record I'd like to State who people with developmental disabilities are. They have severe and chronic disabilities, arising from mental or physical impairments that began before the age of 22. Such disabilities limit major life activities in at least three areas and probably result in the need for long-term services.

Some of those disabilities include cerebral palsy, epilepsy, mental retardation, spina bifida, Tourette's, AIDS, autism, as well as children who have been drug-exposed.

Life itself can be a challenge for any of us, but that is especially so for people with developmental disabilities. In the past, the philosophy was to put these people away in institutions, where they could be protected and have their decisions made for them.

We have taken the blinders off, and we have a vision. What do we see? We see that the more than three million Americans with developmental disabilities want to and should live and work within the community and decide things for themselves whenever possible.

People with developmental disabilities are, apart from their disabilities no different from you or me. They have abilities, competencies and preferences. They deserve a voice in deciding how they live and what sort of services they receive.

And as you mentioned, we did go out and ask them just that. The 1987 Amendments gave us that opportunity to form partnerships with the States. One of these results was the 1990 report which we will be submitting to your shortly. It contains the results of the largest survey ever done of developmentally disabled people. We asked more than 13,000 people to give us a report card on their lives and the services they are receiving.

So what did they tell us? A lot. Perhaps most importantly, that the notion that disabled people want to be dependent, want to be on welfare, is utter fallacy. They want to work, they want to contribute, and they want to do real work. Making kleenex flowers isn't what they are after.

The current situation is appalling. What we did find in that 1990 report is that only 20 percent of developmentally disabled people are working full-time. That's right. And they earn an average of $51 per week. It is appalling.

Is it any wonder that disabled people are seen as vulnerable and dependent? At those wages, they are. But our 1990 report shows that disabled people who hold jobs—real jobs, for real wages—don't suffer that stereotype for the simple reason that it's not true.

I have no doubt that people with developmental disabilities will play an important role in the 1990's as they emerge into viable members of the work force. So we will continue to emphasize employment in our programs, because as a mother from Texas told us about her daughter: "Supported employment works. It allows school staff to train and place students in competitive work sites."

The findings of the 1990 report will be the beacon lighting for our quest for what we call IPI—independence, productivity, and integration into the community. We must educate society to accept some ideas that will be new to them—that people with disabilities can and want to be independent, that people with developmental disabilities can and want to hold real jobs, and that people with developmental disabilities can and want to live within communities just like everyone else.

As another respondent to our survey said, "A man can be blind. A man can be deaf. A man can be brain-damaged. But that isn't the greatest pain. The greatest pain is rejection, to feel that nobody wants you. That is the pain of the heart."

As Dag Hammarskjold wrote, "Only he who keeps his eye fixed on the far horizon will find his right road."

Sure, there are risks in any new ventures, but only by taking some calculated risks, like Columbus did, will we get there.

It is written that "Where there is no vision, the people will perish." We need a vision for people with developmental disabilities. We must stop thinking in terms of what probably won't work and we must be flexible to allow for emerging trends and to take into account what we found in our 1990 report, because what we do now will have an impact on the future.

There is no reason not to shoot for a whole new day for people with developmental disabilities, a day when all barriers will come down. We heard from a parent in Ohio who said her son's school offered job placements in the community, but no way to get them. There was no transportation except to the sheltered workshop, so her son will have to stay in a segregated setting.

We envision a day when attitudes don't stand in the way of where we live or what kind of job we hold. We look to a day when riding the bus or going shopping is just an errand, not an ordeal; a day when all people truly can make their own choices and they really do have equal opportunity.

But things are changing, what with the Americans with Disabilities Act, the 1990 report, and all the other good things we are doing at the Administration on Developmental Disabilities. We are building a foundation. That is why I look forward to working with the subcommittee for the reauthorization of the Developmental Disabilities Program. It is a step in the right direction, even though it is one of many we still have to take.

We will be transmitting legislation for a 3-year extension of the Developmental Disabilities Program at the levels requested in the 1991 budget, and we will be proposing certain amendments to the program.

Thank you very much, and I certainly would be happy to take questions.

[The prepared statement of Ms. McFadden follows:]

PREPARED STATEMENT OF DEBORAH L. MCFADDEN

Mr. Chairman, I am Deborah McFadden, Commissioner of the Administration on Developmental Disabilities, and I appreciate the opportunity to appear before this distinguished Subcommittee to discuss the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act.

Life itself is a challenge for people with developmental disabilities. Over the years, Congress has established national policy on behalf of people with developmental disabilities based on the best thinking of the day. Back in the early sixties, professionals advised Congress to provide money to construct facilities for people with mental retardation. Today, we are managing a program based on a philosophy that more than three million Americans with developmental disabilities should live within the community and advocate for themselves whenever possible. The Administration on Developmental Disabilities (ADD) is dedicated to furthering and enhancing the principles of independence, productivity, and community integration through the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. This legislation must be forward- looking, as we are still answering for our past policies on institutionalization. It must be flexible to allow for emerging trends and the inclusion of existing areas of concern as identified through the State 1990 Reports. This reauthorization of our Act will lead the way into the next century.

Basic to this program is an understanding of the population with developmental disabilities. They are those among us who have severe, chronic disabilities attributed to mental or physical impairments that became manifest before the age of 22. Such disabilities must cause substantial limitations in at least three areas of major life activity and result in the need for services over an extended period of time. Limitations may occur in the areas of self-care, receptive and expressive language, learning, mobility, self-direction, capacity for independent living, and economic independence.

The Developmental Disabilities program has four components to carry out the mission of the legislation: (1) grants to States for planning and coordination of service activities (State Agencies and State Planning Councils); (2) State allotments for a system to protect and advocate for the rights of persons with developmental disabilities (Protection and Advocacy Program); (3) grants to colleges or universities for a national network of programs for interdisciplinary training, exemplary services, technical assistance, and dissemination of information (University Affiliated Programs); and (4) funds for projects to educate policymakers, pursue Federal interagency initiatives,and provide advocacy funds for the Developmental Disabilities Network, and other promising projects that would improve opportunities for people with developmental disabilities.

As Commissioner, I intend to promote innovative activities that support increased independence, productivity, and integration into the community for people with developmental disabilities. It is my hope that my leadership of the Developmental Disabilities program will one day result in the development of models of excellence that promote systemic changes and illustrate farsighted approaches to support individuals with developmental disabilities and their families. My plans embrace partnerships with organizations and agencies at the Federal, State, and local levels, as well as with the private sector, to support activities to assure that persons with developmental disabilities receive needed services and other assistance and opportunities. I intend to challenge the State Planning Councils, the Protection and Advocacy Agencies, the University Affiliated Programs, and Projects of National Signficance grantees to be visionary. I will not be satisfied with grantee statements that say, "We've done that before." I want our grantees to have a positive impact on the lives of the people we serve. Thus, for example, I will continue to emphasize on employment. I am confident that people with developmental disabilities will play an important role in the 1990's as they emerge as viable members of the workforce, thus negating their image as vulnerable and dependent.

We, as an agency, have been striving to make informed decisions focused on improving the quality of life for our Nation's persons with developmental disabilities. We recognize that persons with developmental disabilities have capabilities, competencies, and preferences, and should play an active part in making decisions about the design and implementation of the service supports they receive, as well as in the way they take part in their community.

REAUTHORIZATION OF THE DEVELOPMENTAL DISABILITIES ACT

In order to continue our work on behalf of people with developmental disabilities and their families, Mr. Chairman, we support reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. As you can tell from the impressive list of accomplishments cited, our current legislation has served individuals with developmental disabilities well. We, therefore, propose to strengthen the current legislation by making changes which would clarify several provisions. A legislative proposal will be transmitted by the Secretary to Congress very shortly requesting a three-year extension of the Act. The proposal would:

- extend the due date of the Secretary's annual report from April 1 to July 1, in order to allow the time needed to incorporate into the Secretary's report the State reports, to perform policy analyses, and to secure Departmental clearance.

- add a requirement that each State protection and advocacy system submit to the Secretary, at least every three years, a plan specifying its priorities; describing the relationship between those priorities and other State priorities with respect to activities on behalf of the mentally ill, clients of vocational rehabilitation agencies, and individuals served under the Older Americans Act of 1965, and with priorities under the basic State grant program under this Act; and specifying the intended allocation of State and Federal resources for each priority under the system's plan. This proposal would provide an opportunity for greater coordination between the P&As and the Councils in the development of both plans.

- require each UAP grantee to establish and operate an advisory council, comprised of consumers, parents and guardians, representatives from State P&As, State Planning Councils, local agencies, and private non-profit groups concerned with services for the people with developmental disabilities, for the purpose of assisting UAPs in planning activities that will increase and support the independence, productivity, and integration into the community of persons who are developmentally disabled. These Advisory Councils would facilitate communication and cooperation between the UAPs, the community, and the developmental disabilities network on the planning of UAP activities and programs, and would give consumers a voice in determining their future.

- clarify statutory language to ensure that the appropriate ICF/MR Survey Reports and Plans of Correction to be reviewed by the State Planning Councils are the Independent Professional Review Team Reports.

- clarify language to ensure that it is the State Planning Council, not the State administering agency, who has the authority to hire those staff required by the Council to carry out its functions under the Act.

The Developmental Disabilities Program has accomplished a great deal since the 1987 reauthorization. As a team, we in the Administration on Developmental Disabilities (ADD), the State Planning Councils, the Protection and Advocacy Systems (P&As), and the University Affiliated Programs (UAPs) have concentrated on activities to implement the 1987 Amendments.

1990 REPORT TO CONGRESS

I would like to highlight ADD's special 1990 Report to Congress. Through ADD's individual and combined efforts with the National Association of Developmental Disabilities Councils (NADDC), and the University Affiliated Programs at Temple University, the University of Chicago, and the University of Minnesota, we are witnessing an unprecedented movement toward telling the real story of what it means to have a developmental disability in our society. The Congressional mandate gave States the opportunity to be visionary in their quest to promote systemic change and to enhance the planning and coordination of services for people with developmental disabilities. The reauthorization of the legislation now provides an opportunity to strengthen a unique partnership to carry out the vision we share with States in formulating far- reaching plans and practices to implement the findings and recommendations from each State 1990 Report.

Our activities began when Congress mandated that Developmental Disabilities Planning Councils in all States and territories

(a) conduct policy analyses to determine the scope and effectiveness of Federal and state programs and services for people with developmental disabilities;

(b) conduct surveys of consumers to hear first-hand about their satisfaction with these services; and

(c) hold public forums on the findings and recommendations from these two activities.

Why is the 1990 Report so significant? It is the first time a national survey of such magnitude was conducted drawing from more than 13,000 face-to-face interviews with individuals with developmental disabilities and their familiy members or guardians. The survey elicited many comments from consumers, including the following:

- "Services in Illinois usually are done to or for rather than with people with developmental disabilities and their families." (Illinois)

- "A member of the Texas Planning Council recently scheduled a paratransit ride two months in advance to take him to a friend's wedding for whom he had been asked to serve as best man. Much to his dismay, the ride was two hours late, delivering him to the wedding long after the ceremony had ended." (Texas)

- "My attendants don't do what I need them to do. Sometimes I have to sleep in a chair because my attendant won't help me to bed. I'm afraid that if I fight back, I will lose my attendant and then lose my independence." (California)

- "Recreation is not just for kids. Public departments of recreation need to recognize this. But as an adult with a disability, I need a little more encouragement." (Maine)

I think you will agree that we are witnessing momentous changes in society particularly as they impact people with disabilities. The Americans with Disabilities Act embodies one such change. The reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act and the information from the 53 1990 State Reports are important not just to our four programs, and people with developmental disabilities . I believe the act will usher in a new day for all people with developmental disabilities.

- A day when this country will hold the same promise for every individual;

- A day when all the barriers come down; when attitudes don't stand in the way of where we live or what kind of job we have; when taking the bus or going to the supermarket won't present a single obstacle.

- A day when the choices people make are truly their own.

The climate is right to re-examine our disabilities programs. The 1990 Report to Congress will present findings we believe will light the way toward achieving the vision of full independence, productivity, and community integration for individuals with developmental disabilities.

The 1990 Report will include a thorough policy analysis of the State reports on seven major life areas: (1) income; (2) education; (3) employment; (4) housing; (5) individual and family support; (6) transportation, and (7) civil rights. The information comes from the collective efforts of Federal, State, and local officials, private sector providers, and the families and friends of people with developmental disabilities at numerous meetings and forums held all across the country. Most important, the 1990 Report reflects the opinions of our consumers.

A few more quotes from the 1990 State Reports illustrate both the progress we have made and the distant we still have to go before the goals of the Developmental Disabilities Act will be achieved:

- "The county is telling me to put my kids into foster care because I have no help. I am finding it hard to deal with all three kids. Foster parents are getting respite care before natural parents." (Minnesota Consumer)

- "Funding for people with developmental disabilities is not flowing to where most of these citizens and their families live - in the community." (Illinois Report)

- "We have an 11-year-old son who has cerebral palsy and is quadriplegic...But we don't get much help from anyone because they all say, Sorry, you make too much. Then in the paper they say, We can't find families that need this service. (Iowa parent)

- "Mr. ________ is being cared for by an elderly sister. He goes to a day activity program. However, he never gets to go out on weekends and evenings due to his sister's inability to transport him. He said he would like to go out more often and is sad that he can't." (Ohio Report)

- "Many job sites and work spaces are physically inaccessible." (Vermont Report)

- "When you set about to make a change, please don't let them go backwards. We have come a long way and we don't want to lose what we've gained for our kids." (Utah Consumer).

These quotes alone show why the information in the 1990 Report to Congress will be of interest to a number of Federal agencies, including the Departments of Labor, Justice, Housing and Urban Development, Transportation, and Education. Several programs within the Department of Health and Human Services are also referenced in the State reports, including the Health Care Financing Administration, Social Security Administration, Public Health Service, Family Services Administration, and the Office of Human Development Services.

I am sure you are already receiving copies of individual reports from the states and territories, providing "report cards" on service delivery to persons with developmental disabilities within your respective states.

STATE PLANNING COUNCIL ACTIVITIES

Beyond the 1990 Report, the State Planning Councils have also been carrying out the program's other legislative mandates.

The 1987 legislation clarified and strengthened the State Planning Councils independence to carry out their advocacy role and reaffirmed their role as a bridge-builder and advocate for systems change. Councils have begun to identify trends that will influence policy reform and advocacy. The current areas of interest include: community-based care and community living; employment and supported employment; training of professionals and direct care providers; family support; Medicaid reform and Medicaid waivers; prevention; early intervention and services for children; accessibility and legal rights and self-advocacy.

The State plans present specific activities in the four Federal priority areas -- employment, case management, child development and community living. Councils also report that States are taking the opportunity to establish priority areas on such topics as family support, independent living, and public awareness.

The following examples of State Planning Council accomplishments illustrate how Councils are concentrating their efforts on advocacy and systems change:

- In FY 1988 the Iowa State Planning Council formulated specific governmental priorities, which included increased State hiring of persons with developmental disabilities. The Council successfully demonstrated projects on supported employment and competitive employment and also planned, developed, and conducted a symposium on supported employment.

- In FY 1989 the Iowa legislature enacted legislation creating a family support subsidy program with an initial appropriation of $75,000. Through joint efforts of several advocacy organizations as well as the Iowa Department of Human Services, the program was reauthorized with an appropriation of $400,000. The Council will continue to work with legislators and other individuals to modify this program's eligibility requirements to include children with developmental disabilities who are not in special education programs.

- In FY 1988 the Minnesota State Planning Council completed a State survey of case management and funded seven grants that produced a number of promising outcomes, including a microcomputer-based information system for case managers and a program of volunteer monitoring of the quality of services provided through the case-management process.

- In FY 1989 the Minnesota Developmental Disabilities Planning Council funded the volunteer monitoring project. Nineteen volunteers were trained and each made three or four visits to residential or vocational facilities. Eleven facilities (eight residential and three vocational) in seven different counties were monitored.

- In FY 1988 the Utah State Planning Council established a state-wide network of family-to-family counselors to counsel families with children or adults with developmental disabilities as they move through various of transitional periods. The goal of the program, the Family-to Family Transition Project, is to make community living more feasible and decrease the probability of institutionalization.

- In FY 1989, through the efforts of the Utah Council Legislative Coalition, the Legislature is adopting a new attitude toward keeping children and young adults with developmental disabilities at home and is increasingly willing to fund supports for those families. A bill was passed giving families who support members with developmental disabilities an extra tax exemption. Additionally, legislation was passed on ICF/MR size limitations.

PROTECTION AND ADVOCACY SYSTEM ACTIVITIES

Protection and Advocacy Systems represent one of the major strengths of the disability movement, especially in support of advocacy for persons with developmental disabilities. The P&As have been successful in negotiating 90 percent of their cases without resort to litigation. These agencies served approximately 61,400 persons in 1988, and 136,960 persons were served by class action suits. Our current national policies are due in large part to the quality of advocacy by consumers, families, and other concerned citizens. It is the P&As that ensure the rights of persons with developmental disabilities remain a reality and that public policy is translated into meaningful action. It is through their vigilance and training of others that individuals with developmental disabilities really experience the protections they are guaranteed by the Constitution and by the Bill of Rights mandate of the Developmental Disabilities Act.

The P&As have engaged in many activities for people with developmental disabilities.

- Through the concerted efforts of the Iowa P&A agency, residents with developmental disabilities in health care facilities are now assured of greater protection of their personal rights and private property. The Iowa legislature passed a law that enables residents to recoup funds or property used without the written consent of the resident or the resident's guardian. This legislation also requires complaints of alleged abuse or neglect to be filed with the P&A agency. This legislation affords significant protection of the rights of persons with developmental disabilities who must remain in health care facilities.

- The Alabama Advocacy Program advocated on behalf of a homeless man with mental retardation after he was treated at a local hospital for exposure to cold weather. At the time of the P&A's involvement in the case, no family could be found for the man, who was refusing any services. The P&A negotiated to place the man in a group home, provided counseling, and secured the medical attention the man needed to participate in a day activities program.

- The Georgia Advocacy Office learned about Andy who was 13 months old and living in an institution. His birth family had decided they could not raise him and gave up parental rights. In his first year of life Andy survived nine major surgeries and faced several plastic surgery operations to give him a more normal face. The P&A office worked to find a family for the boy. One day, a family with a three-year-old of their own met Andy. The youngster said, "He has lots of boo-boos on his face. His eyes are broken, and his nose is all smooshed. We should take him home." They did.

The 1987 Amendments included several key provisions for the P&As to implement, including the establishment of grievance procedures, which all P&As did. Persons with developmental disabilities can now register their complaints about available P&A services and the priorities for establishing such services. The P&As welcomed the formation of these procedures, was welcomed, as the P&As believing it was important that they be held to the same standards of accountability as the service providers with whom they were interacting.

The 1987 Amendments also illustrated Congress's interest in outreach to minorities and other populations underserved by the P&As. Several notable activities have been initiated in this area:

- During September 1989, a public forum endorsed by the Navajo and Hopi Tribal Councils was held to discuss ways to provide services urgently needed for Navajo and Hopi Native Americans with developmental disabilities. A background paper for meeting participants emphasized the need to create of a local, reservation-based P&A staff with legal professionals who speak Navajo and Hopi languages and are sensitive to their cultural values. A pilot demonstration project is currently being developed by National Association of Protection and Advocacy Systems (NAPAS).

- Other States have also documented the needs of Native Americans with developmental disabilities who live on reservations throughout the United States. Funding strategies that would allow P&A services to reach these reservations effectively are also being considered. The P&As have included the needs of Native Americans in targeted States as one of their priorities.

- **A P&A People of Color Caucus had several audio-teleconferences to advise P&As on activities in minority issues and to lend their expertise in effectively serving minority clients in a "culturally relevant and sensitive manner." On a national level, these systems are looking to improve staffs' skills training on minority issues.**

P&As must address continuing as well as emerging issues. Such activities as negotiation and, in extreme cases, litigation must be undertaken in order to protect the rights of persons with developmental disabilities. Activities of note include:

- ADD recently awarded a one-year grant to the National Association of Protection and Advocacy Systems (NAPAS) to provide training and technical assistance to P&As. These activities will include continuation of peer reviews and consultations, management training, and brokering expertise. Training on legal strategies, issues, and policy analysis on Fair Housing and Nursing Home Reform will be provided. Efforts at coordinating cooperative efforts between P&As and Long Term Care and Ombudsman programs for elderly persons with developmental disabilities will be paramount.

- **Additionally, NAPAS will be developing standards to measure both the qualitative and quantitative performance of P&As.**

UNIVERSITY AFFILIATED PROGRAM ACTIVITIES

The University Affiliated Program (UAP) continues to strengthen its efforts to "make a difference" in the lives of persons with developmental disabilities and their families. There is a spirit of cooperation between ADD and the Directors of University Affiliated Programs and Satellite Centers. The accomplishments of this program are many since the last reauthorization of the Developmental Disabilities Act. For example, in Fiscal Year (FY) 1988, there were over 76,000 people with developmental disabilities served in UAP operated clinics and community-based service settings. Additionally, 2,700 products (books, journal articles, audio-visual and public awareness materials) were disseminated in FY 1987-88; and in FY 1988 alone, the equivalent of approximately 50 person years of effort was provided in the form of technical assistance.

UAPs continue to develop innovative methods of leveraging their core grants (current ratio of core dollars to total UAP funding: $1 to $21) to increase the resources that State, county and local agencies use to address issues affecting the lives of persons with developmental disabilities. UAPs utilize a variety of approaches in support of improving these individuals' lives. Consumers are seen by UAP faculty and staff within their own clinics, within community-based service agencies and within the private and public school systems. Additionally, UAPs provide training support at three levels (1) intensive interdisciplinary graduate and undergraduate training, (2) university classroom training, and (3) community-based outreach training.

When the UAPs were initially developed, their focus was on children with developmental disabilities and their families. This focus has broadened in recent years to include adolescents and adults. Prevention of developmental disabilities has been an implicit part of the UAP purpose from their very inception. Research and prevention were areas of concern, along with manpower and community-based programs, that were given attention in the report of the President's Panel on Mental Retardation in 1962. It was in this report that the concept of the UAPs was first publicly formulated. Examples of UAP prevention activities include the following:

- The Missouri UAP developed, published and updated the Missouri State plan for prevention, and is home for a Prevention Institute, funded by the Missouri State DD Planning Council, which is developing public information and indentifying and analyzing effective models for prevention programs.

- The New Jersey UAP is developing a prevention library under a contract with the State's Office of Prevention.

- The Iowa UAP is an integral component of the State planning project funded by the Center for Disease Control.

- The Kansas UAP has been instrumental in the establishment of a prevention planning priority within the Governor's Office which resulted in a State prevention planning conference in December, 1989.

The population with developmental disabilities is aging, and persons over the age of 50 now constitute the fastest growing segment of the population served by UAPs. Therefore, a recent challenge for the UAPs has been to extend the orientation and capacity of the UAP system to cover the full life span, ranging from pre-natal care to issues concerning the elderly.

The 1987 Amendments provided several new avenues in support of these new directions. The training initiative projects were one of those new opportunities.

In FY 1989, ADD selected 31 UAPs to receive supplemental grant awards to support training projects in the areas of early intervention, programs for elderly persons with developmental disabilities and community-based programs (training direct care staff).

The accomplishments of the UAP training projects reflect individual and collective efforts to bring about positive impact on the lives of clients and consumers, to foster system change in service delivery systems, and to leverage additional resources from other Federal, State and local sources.

The following examples highlight the UAPs successful implementation of the training initiative projects:

- Projects are increasing the participation of parents and family members in the planning of services, curriculum development and the training of staff. Parents are being placed on advisory boards and task forces to express their input on issues of policy and project implementation.

- Projects are benefitting from leveraging resources of funding for investments that are not covered by the grants themselves. A primary goal was to increase the fiscal and other resources allocated to these initiative areas within each of their respective States.

- State-wide training programs are being developed to train staff from developmental disability agencies to impact systems of delivery. The overriding goal of the training initiative projects was to increase the national pool of well trained professionals, paraprofessionals and direct care workers. In Fiscal Year 1989, UAPs reported that over 364,000 persons received training from the UAPs.

- Efforts are directed towards impacting generic service delivery systems by increasing the likelihood that persons with developmental disabilities receive services from these agencies. Several of the training initiative projects targeted as one of their goals the improvement of consumer services. In Fiscal Year 1989, UAPs reported that their overall program activities had served 85,000 consumers and their families.

Another new provision was to allow for an expansion of the UAP network. A peer review process was established by regulations

regulations (Final Rule, November 20, 1989) to review applications for UAP grants. ADD published a program announcement in both FY 1988 and 1989 to solicit applications for the consideration of UAP or Satellite Center funding from any public or non-profit organization associated with or an integral part of a college or university which is located in a State, Territory or Insular Area not now served by an ADD-funded UAP or Satellite, or consideration of funding to conduct a feasibility study to establish a UAP or Satellite Center.

In FY 1988, ADD grant funds were awarded for three (3) new core UAPs (University of Arkansas, University of Hawaii, University of Illinois); one (1) Satellite Center (University of Idaho) and two (2) Feasibility Studies (University of New Hampshire and the University of North Dakota).

In FY 1989 ADD funded two (2) new UAPs (University of New Hampshire and the University of Texas/Austin) and one (1) Feasibility Study (Oklahoma State University) - was funded in FY 1990.

ADD anticipates the publication in the Federal Register of its FY 1990 program announcement to expand the UAP by March 30, 1990. Funding decisions on new programs are anticipated to be completed by June 30, 1990.

PROJECTS OF NATIONAL SIGNIFICANCE

The Projects of National Significance component of the Developmental Disabilities program provides ADD the opportunity to focus funds on needed areas of concern for individuals with developmental disabilities, their families, the Developmental Disabilities program network, and other interested public or non-profit private entities.

I would like to share with you an overview of the FY 1988-1989 accomplishments for the Projects of National Signficance.

The priority areas included: (1) family support; (2) quality of life; (3) culturally sensitive projects; (4) employment; (5) HIV/AIDS; (6) staff training; (7) international/technology transfer; (8) information and referral; (9) technical assistance; and (10) ongoing data collection systems.

Accomplishments of selected projects in priority areas are highlighted below:

- Family Support - The Human Services Research Institute is addressing the need for educating policymakers and empowering families. The project is identifying necessary means of family support which will enable families to provide care at home, allow children to return home from outside placements, and assist people with developmental disabilities to maintain their own homes or families. The project is also designing and implementing materials to increase policymakers awareness of the most critical issues surrounding family care and is providing technical assistance for implementing family support policies and practices.

- HIV/AIDS - Boston Children's Hospital is providing service delivery to infants with congenital HIV infection, older children with acquired infection, youth and young adults at risk, infected adults with mental retardation and primary care providers. Project products include: guidelines on developmental services for children and adults with HIV infection; public policy affirmations (affecting the planning and implementation of developmental services for children and adults with HIV infection); and, technical reports on developmental disabilities and HIV infection.

- Quality of Life - The University of Georgia is providing outreach through Georgia Senior Centers to demonstrate that old age for people with developmental disabilities can be a time of fulfilling activity and creativity. The project will develop, implement, research and disseminate drama, art, dance and fitness programs to improve the quality of life and integration into the existing service system for people with developmental disabilities.

- On September 18, 1989, a notice soliciting comments on ADD's proposed priority areas for FY 1990 Projects of National Significance was published in the Federal Register. Following a 60-day period to allow for public comments on the proposed priority areas, ADD received a total of 35 letter and 127 individual comments from advocacy agencies, educational systems and government agencies. The comments helped highlight the concerns of the developmental disabilities field and have been extensively used in refining the final priority areas. The priority areas for FY 1990 are:

- Projects to Assist and Educate Policymakers: Self-advocacy and Empowerment--A Process to Strengthen Families:

- Projects to Develop an Ongoing Data Collection System;

- Technical Assistance to State Developmental Disabilities Planning Councils, State Protection and Advocacy Agencies, and University Affiliated Programs;

- Community Integration Projects;
- Pediatric HIV/AIDS Projects;
- Services to Minorities with a Developmental Disability Projects.

The FY 1990 announcement was published in the Federal Register on March 8, 1990, and funding decisions are expected by the end of July.

FEDERAL COORDINATION

Mr. Chairman, I have been pleased with the actions ADD has taken to strengthen and extend our efforts to assure greater coordination and collaboration with Federal Departments and agencies. I would like to identify some of those efforts.

Interagency Committee on Developmental Disabilities. The Interagency Committee on Developmental Disabilities (ICDD) was established by the Developmental Disabilities Act of 1984. It is co-chaired by the Commissioner of the Adminstration on Developmental Disabilities and the Assistant Secretary for Special Education and Rehabilitative Services. The purpose of the ICDD is "...to coordinate and plan activities conducted by Federal departments and agencies for persons with developmental disabilities."

In order to more effectively meet this mandate, the ICDD periodically established subcommittees to focus on specific issues that involve two or more Federal agencies and to recommend courses of action. At present, subcommittees have been established for fire-safety, advocacy (protection and advocacy), and supported employment. In addition, the ICDD has been working with the Interagency Committee on Disability Statistics to serve the same purpose. A subcommittee is currently being formed in the area of information and referral.

In most cases, these subcommittees become involved in issues that focus not only on people with developmental disabilities, but on issues facing people with disabilities generally, and on issues facing persons who are aged. More often than not, an issue that affects one of these groups affects all. For example, advocacy programs exist in the National Institute of Mental Health, the Administration on Developmental Disabilities, the Rehabilitation Services Administration, and the Administration on Aging. There are many common areas, e.g., training, where there are opportunities for cooperation and coordination.

The subcommittees are meeting regularly. One of the more important accomplishments during the last year was the funding of a two-year project to evaluate the Fire-Safety Evaluation System for Board and Care Homes. Through an Interagency Agreement, six agencies have contributed to this project - NIMH, ADD, AoA, OSERS, SSA, and HCFA. The subcommittees have also developed recommendations in the area of disability statistics and are working on developing improved methods of coordination in other areas.

The ICDD will meet in early May to consider the operations of the subcommittees and to chart future activities.

HHS Disability Working Group. ADD has been participating in a recently formed Department of Health and Human Services (HHS) Disability Working Group. This group is examining departmental programs and policies for people with disabilities and recommending ways to improve the service system which will result in recommendations being forwarded to the HHS Policy Council. The Working Group has established three subcommittees to examine access to health care, employment, and community-based services. Because each of these subgroups has important implications for people with disabilities, ADD has participated in each of their deliberations.

ADD has taken a lead role for the community-based services subgroup and is currently examining ways to improve coordination of services. We are also working with other agencies concerned with Information and Referral (I&R) Systems(e.g., Administration on Aging and the National Institute on Disability and Rehabilitation Research) to discuss how to improve I&R systems and how to effectively coordinate with other I&R systems.

Memorandum of Understanding with the Administration on Aging. The 1987 Amendments to both the Developmental Disabilities Act and the Older Americans Act encouraged the coordination of activities between agencies concerned with aging and with disabilities on the Federal, State, and local levels.

On June 22, 1989, a Memorandum of Understanding (MOU) was signed by officials at ADD and AoA to jointly develop and implement initiatives which cultivate a better understanding of programs serving people who are elderly and people with developmental disabilities between the National Network on Aging and the Developmental Disabilities Network; and to undertake the development of other collaborative activities which promote the independence and well-being of older people with developmental disabilities.

As a result of the MOU, ADD and AoA will jointly fund collaborative projects in FY 1990 between State Developmental Disabilities Councils and State Agencies on Aging to develop State and local planning linkages which will improve services to older persons with developmental disabilities and to older parents of adults with developmental disabilities.

Applications are being solicited from the Developmental Disabilities State Planning Councils or State Agencies on Aging for a joint project to develop collaborative models which demonstrate and document successful strategies for coordinating programs and services. Models will describe:

- efforts of ADD and AoA networks to develop State and local planning linkages;
- barriers to collaboration and coordination and methods used to overcome barriers;
- linkages with other relevant agencies who share concerns in the area of developmental disabilities and aging;
- examples of successful integration of older persons with developmental disabilities into Developmental Disabilities Act and Older Americans Act programs.

It should be noted that there is also significant work being done in the aging area through the UAPs and the training grant authority. In September, 1988, ADD awarded Aging Initiative training grants to seven (7) UAPs. These UAPs have taken the first steps towards establishing a new infrastructure. This infrastructure will ultimately consist of personnel who are skilled in working with adults and older persons with developmental disabilities, services that are targeted to meet both the generic and the specialized needs of this population, and resources that are adequate to support the personnel and services. Activities of several Aging Initiative training grants are highlighted below:

- Missouri UAP has developed an Interdisciplinary University Based Training Program with the Center on Aging Studies to promote appropriate training for professionals.
- Montana Satellite Center is training professional and paraprofessional direct care providers with particular attention being given to the provision of services in rural/remote areas.
- Wisconsin UAP (Waisman Center) is collaborating with Developmental Disabilities and Aging agencies, conducting training programs for professionals and paraprofessionals and is establishing the Waisman Clinic on Aging and Developmental Disabilities.

Interagency Initiative with NIMH - P&A Technical Assistance. An Interagency Agreement was signed February 7, 1990 between ADD and the National Institute of Mental Health (NIMH) P&A Program. The purpose of this agreement is to provide $25,000 in supplemental funds to a recently funded grant to the National Association of Protection and Advocacy Systems (NAPAS) which will provide specific technical assistance and training activities to P&As that are supported by both ADD and NIMH.

The focus of this agreement is on P&As that serve mentally ill individuals in residential facilities. The technical assistance and training activities will include internal program development and management procedures, coordination and facilitation of the annual meeting for P&A coordinators for the mental illness program, and training on legal strategies.

Interagency Initiative with NIST - Fire Safety In Board and Care Homes. ADD is involved in an interagency agreement on fire safety in board and care homes with the Center for Fire Research, National Institute of Standards and Technology (NIST), (formerly the National Bureau of Standards),Department of Commerce. The purpose of this interagency agreement is to assure a high level of fire safety in board and care homes, and to decrease the cost of achieving this safety. As part of the activities conducted under this agreement, information will be gathered and assurances will be provided that the fire safety requirements in board and care homes are based on the new requirements of the Life Safety Code.

ADD Initiative with HRSA - Minority Health Professionals Entering the Field of Developmental Disabilities. An ADD agreement is about to be signed on minority health training opportunities with the Bureau of Health Professions, Health Resources and Services Administration (HRSA), Public Health Service. The purpose of this agreement is to promote greater cultural diversity by increasing the number of minority health professionals entering the field of developmental disabilities.

The need to increase minorities in the health professsions will be facilitated by combining the financial and programmmatic resources of HRSAs Health Careers Opportunity Program (HCOP) and ADD's UAPs.

I also look forward to working with this Subcommittee on reauthorization of the Developmental Disabilities Program. In closing, I want to assure you that our policies will continue to focus on attaining the complementary goals of providing flexibility at the State and local level and supporting improved program effectiveness in recognizing the needs, potential and accomplishments of people of all ages with developmental disabilities.

As Commissioner of the Administration on Developmental Disabilities, I am determined to follow my predecessors in ensuring that both concrete and image barriers are being dismantled, and that previously thwarted pathways are opening to allow for new challenges and opportunities that give meaning and purpose to the lives of people with developmental disabilities.

Thank you, Mr. Chairman, I would be happy to answer any questions.

Senator **Harkin**. Ms. McFadden, thank you very much for your statement.

I think we obviously share the same vision for people with developmental disabilities. It is obvious you understand the significance of the 1990 reports, the ADA bill, early intervention and providing options in community settings.

What I don't understand is why the Administration's proposed budget for the DD Act has no relationship whatsoever to this vision. How can we implement the 1990 report, how can we gear up for implementation of the Americans with Disabilities Act, how can we gear up for early intervention programs, when we have no funding increase whatsoever for these critical programs?

We already have waiting lists for the Protection and Advocacies, and a lack of qualified personnel. Let me refer to my budget table here. The appropriation last year was $98.477 million; the fiscal year 1991 request of the Administration is $98.477 million—a zero increase.

It is nice to have a vision, but when you don't have anything to back it up, what good is the vision?

Why do we have a level funding request?

Ms. **McFadden**. I think it is important that we do things in incremental steps, and certainly the results of the 1990 report is an area that we will be looking at in determining how the moneys should be directed and where we put them. That's where we are currently looking for guidance right now.

We do a lot with our money, Mr. Chairman. We know how to make a dollar go far.

Senator **Harkin**. So you don't need anymore increase over the $98.477 million—I'm not trying to put you on the spot, but let's be fair about this. We're all trying to accomplish certain goals, and when we've got all these things coming down the pike—which you even talked about in your statement—I'd like to know how you're going to do it with the same amount of money you had last year. You say you can, and you don't need any more money; that we can accomplish all these wonderful things, with the increase in inflation and keeping it at level funding. Well——

Ms. **McFadden**. Mr. Chairman, I would like to give you an example. It is our job to find new, innovative programs and new ways of allocating money and setting up new model programs.

In one of our UAP programs, we took a look at community living, which in fact is very expensive, and found two men who had been living at home for 45 years with their sister, and when she had a stroke, they were about to place them in a community home, which would individually have cost somewhere between $100,000 and $150,000 apiece. Our UAP's found a way to number one, keep these gentlemen in their home—which is what we are after, community living—keep them where they had been for 45 years, and keep them in the generic programs. We accomplished that together with these two men for $30,000 a year. In fact, we now have five programs set up in that same State, with a savings of over $1 million for that State.

We'll have to be creative.

Senator **Harkin**. Well, even with the passage of the ADA bill, you've got waiting lists here for the P&A's. And you are going to provide all those services that you are going to have to provide in a creative manner. So you are saying that you don't need any more money, that with last year's level you can accomplish everything that you want to accomplish.

Ms. **McFadden**. We requested level funding.

Senator **Harkin**. Let me ask you about the University Affiliated Programs, which you mentioned. I assume you agree that the University Affiliated Programs, the Planning Councils and the P&A's are all important programs—I don't even have to ask you that; I know you believe that. I also would assume that you would agree that in those States where these programs exist, it is an interrelated force, where you have the Planning Councils, the P&A Systems, and the University Interrelated Programs; they are an interrelated force in those States.

However, the University Affiliated Facilities exist in only 44 States. In your opinion, in those States in which all three programs are not present, do you think it is important to continue the policy in the current law which provides a priority for expansion of the program?

Ms. **McFadden**. Yes.

Senator **Harkin**. With regard to the P&A System, would you agree this is an essential component of the DD Act?

Ms. **McFadden**. Absolutely.

Senator **Harkin**. Absolutely. And I would also assume that you believe it is important for the P&A System not only to operate, but to operate effectively, and to protect the legal and human rights of persons with developmental disabilities.

Ms. **McFadden**. Absolutely.

Senator **Harkin**. Let me just ask you a hypothetical question. At one time you worked for an oil company; is that right?

Ms. **McFadden**. Correct.

Senator **Harkin**. Let's say that an employee of an oil company was assigned the responsibility of enforcing the Federal environmental protection laws. I would hope you would agree that the delegation of such authority to an employee of a company that was regulated by such laws would be inappropriate for two reasons. First, the lack of independence between the regulator and the industry has the potential for creating a situation in which the employee might be reluctant to aggressively carry out those kinds of responsibilities. Second, even if such a conflict did not exist, it creates the perception of a conflict and undermines the public confidence in those companies and in the companies' personnel enforcing the environmental protection laws.

Now, let me just ask if it would be in order for the Protection and Advocacy System to aggressively protect the legislative and human rights of people with developmental disabilities that they must have independence from those agencies or entities who might be violating the legal and human rights of people with disabilities. Do you agree with that?

Ms. **McFadden**. I would.

Senator **Harkin**. Thank you.

Senator Durenberger.

Senator **Durenberger**. I just have a couple of questions that relate to the substance of our reauthorization. One, I referred to in my opening statement, is the concern that I have about the prevalence of developmental disabilities. The reason I raise that is not because this is the Census here, and gosh, wouldn't it be wonderful to go out and count folks and put them in categories, but because the uniqueness of this particular Act make it attractive, and the way the Federal policy system works, anything that is attractive, a lot of people will seek the benefits of, and as the chairman has indicated, if there aren't enough resources to make it work, then you create some problems.

I sit over in the Finance Committee, trying to deal with medical access. Thus, I know how much more money we spend in Title XIX on these problems than we do here. So I am curious to know what you, or the Secretary is going to be doing about current efforts underway for a national survey of persons with developmental disabilities. Is there something in the works that I may not know about that will help us define who all these folks are on a national basis?

Ms. McFadden. Are you speaking of the 1990 report?

Senator Durenberger. Yes.

Ms. McFadden. Yes. Our survey will help define what these people are getting or not getting in services, where the barriers are, where there might need to be more coordination. That is in seven different areas, and it is extensive information. In fact, the DD Councils, I have said, are in need of respite care after collecting this information. It will take us a long time to analyze it and where we go. As the chairman said, it will be the blueprint for us for this next decade, where we go in policies.

It will not give us a count, though, of how many developmentally disabled people are out there, but it will give us a picture of what their needs are.

Senator Durenberger. As I said, I wasn't as concerned about the count as I was about determining who is eligible for various types of support. Is that what this study is going to give you?

Ms. McFadden. It will look at eligibility requirements for different programs, are they working together, are they working in conflict with each other. There are some suggestions from certain States. Minnesota has some outstanding recommendations. We will be able to look and see can we better coordinate the eligibility requirements so people do in fact get better services.

Senator Durenberger. Do you have an elaboration?

Ms. McFadden. Yes. And you are asking about an additional report—there is another report, but it is in the developmental stages. It is not refined yet.

Senator Durenberger. Well, I've got something here—"A National Survey of Persons with Developmental Disabilities." It is a final report of a design project submitted to the Assistant Secretary for Planning and Evaluation.

Ms. McFadden. That's under development right now.

Senator Durenberger. What does that mean?

Ms. McFadden. We are looking at a number of different areas. It is not finalized.

Senator Durenberger. That sounds very evasive. What does it mean in the practical sense?

Ms. McFadden. The idea is there—we have meetings scheduled saying what should be in this report, how should we go about it, but nothing is——

Senator Durenberger. Has somebody made a decision that there will be a national survey of persons with developmental disabilities?

Ms. McFadden. I'll have to submit that for the record.

Senator Durenberger. You don't know whether that decision has been made.

Ms. McFadden. I'll submit it for the record.

Senator Durenberger. The other question was with regard to the Bill of Rights. I was not on the subcommittee when the Bill of Rights for people with developmental disabilities was designed, but as I listen to Charlie and Colleen Wieck from my own State of Minnesota and people like that talk about this, I know a lot has changed in the last six years, and I am wondering the degree to which the Administration has re-looked at the Bill of Rights, found opportunities to recommend to us that it might be made more specific and more helpful.

Ms. McFadden. Our analysis of the current legislation where it stands is it is good. We have a few areas that we'd like to tweak a little bit. Certainly, in the area of people with disabilities, the area that both the TCB and we looked at, is "People First" language and increasing opportunities for the independence, productivity and integration.

There are no major changes that we are recommending.

Senator Durenberger. Do you know what I'm talking about when I talk about the Bill of Rights?

Ms. McFadden. It is part of our law, yes, sir.

Senator Durenberger. Yes. Was your answer responsive to that? I mean, do you have recommendations or changes in the Bill of Rights in whatever proposals you have made to the subcommittee?

Ms. McFadden. We have no changes.

Senator Durenberger. You have no recommendations for changes. OK, thank you.

Senator Harkin. I haven't heard of any recommendations.

Ms. McFadden. No, we don't.

Senator Harkin. Is there anything else you wanted to add, Ms. McFadden?

Ms. McFadden. No.

Senator Harkin. Thank you very much for being here.

Senator Harkin. Next, we have a panel: Dr. Elizabeth Boggs, testifying on behalf of the Consortium on Citizens with Disabilities; Dr. Charlie Lakin, from the University of Minnesota, testifying primarily as a consumer, but will draw upon his research funded in part by Projects of National Significance; and Helen Coburn Roth, from Logan, UT, testifying as a consumer. Ms. Roth is the director of a Northern Utah Independent Living Center.

First of all, let me just say that Senator Hatch is still in Atlanta—he must be fogged in or rained in—and could not be here this morning, Ms. Roth. He wanted to be here specifically to introduce you. And Senator Hatch has a statement which he wanted to put in the record regarding Ms. Roth—well, I might as well read it now.

He says, "I consider it a great privilege to be able to introduce Ms. Helen Coburn Roth as a consumer of developmental disabilities services. Ms. Roth is particularly sensitive to the needs of individuals with disabilities and their families. She is a champion of consumer participation and believes that persons with disabilities should have the responsibility to determine their own needs and select productive courses of action that lead to a life of quality and dignity. Ms. Roth holds a B.A. degree in psychology from Utah State University, and a master's degree from Pennsylvania State University. She pursued a doctoral program at Radcliffe College at Harvard University. Ms. Roth has devoted her life to social and human service issues. She has been employed as a psychologist and as a human service professional in various capacities. However, a large part of her life has been spent volunteering her time and talents to health, community and consumer causes at the State and local level. Ms. Roth was the founder of the Cache County Handicapped Action Council and is Executive Director of the Northern Utah Community Action Program. She has been a board member and advocate for numerous programs addressing the needs of senior citizens with individual disabilities, and low-income housing and employment programs."

We welcome you here today, and I apologize that Senator Hatch is evidently locked in in Atlanta because of weather.

Let me first recognize Dr. Elizabeth Boggs. I have your statement, and it will be made a part of the record in its entirety. We would ask you to proceed, and then we'll go down the line to Mr. Lakin and Ms. Roth.

STATEMENTS OF DR. ELIZABETH M. BOGGS, PH.D., HAMPTON, NJ, ON BEHALF OF THE CONSORTIUM FOR CITIZENS WITH DISABILITIES; DR. CHARLIE K. LAKIN, RESEARCH DIRECTOR, INSTITUTE ON COMMUNITY INTEGRATION, UNIVERSITY OF MINNESOTA; AND HELEN COBURN ROTH, LOGAN, UT

Dr. BOGGS. Thank you very much, Senator.

I am particularly pleased to be invited to represent the Consortium for Citizens with Disabilities on this occasion since we are approaching the 20th anniversary of the enactment of the original Developmental Disabilities Act, which occurred on October 30th, 1970. I think the two decades, the one generation of developments over that time are truly remarkable and are a great tribute to the members of the Congress including by no means least yourself for their diligent support of what has seemed at times a minority interest.

The act has undergone some major revisions over that period of time. In 1975, we added the P&A Systems; in 1978, we rewrote the definition; in 1984, Congress asked to have certain priorities specified that the State Councils would address or choose to address among them; and in 1987, very important changes were made which brought about the 1990 reports to which Dr. McFadden has already referred.

You yourself gave an excellent introductory statement, and you mentioned that this is indeed a very small program compared to the importance and complexity of the problem. I was interested in your figure because the authorization for the Basic State Grant Program alone in 1972 was $105 million in 1970 dollars.

Senator HARKIN. One hundred and five?

Dr. BOGGS. That was the authorization level, yes.

Senator HARKIN. Just for the Basic State Program?

Dr. BOGGS. Just for the Basic State Program. We can talk later, if you like, about what was really intended at that time and what didn't happen, but what has happened has been really quite remarkable. And it all devolves around the diversity of needs and complexity of needs of people whom we call people with developmental disabilities.

The four components of the program have been fairly stable entities since 1975, and our testimony addresses each of these, and in addition, three of them will have spokespersons of their own in the next panel, so I won't go into detail about those particular ones.

Let me say a word or two about the 1990 reports. We really don't know what is in them yet. We'll find that out in a few weeks, or at least a month or so, and I assure you that we in the field are as eager as you are to know really what they all say.

One thing I think is fairly clear. One of the objectives was to talk about the unserved and the underserved. It is fairly clear that the category of disability has relatively little to do with whether you are unserved or underserved. People in all categories are out there in large numbers who are inadequately served, and indeed, the waiting lists for supported community living arrangements for adults with developmental disabilities have been growing by leaps and bounds even while we were writing the 1990 reports.

One of the things the 1990 reports tried to do was to ascertain the extent and nature of the participation of people with developmental disabilities in the more generic type programs—the programs authorized under the Social Security Act, under the Housing Act, under the Education Acts, and so forth. And as I will mention later, this whole question of relating the generic systems to people with specialized needs is an ongoing dilemma that we face and that the Developmental Disabilities Act and the Councils and their activities and their composition was designed to reflect and address.

In particular, the issue of case management has been a very fluid one. It is an area that you have designated as a priority setting. Different people defined case management in different ways. It is clear that our concepts of case management ought to be broadened and made more flexible, more adaptive to the variety of needs that exist.

Several of the organizations that belong to the Consortium also are the sponsoring organizations of the Accreditation Council on Services for People with Developmental Disabilities, and our most recent revision of the standards of that organization provide for a broader concept of case management, including self-case management, the possibility that an individual would become more capable of managing his own service system, which indeed is the normal model for you and for me. We are our own case managers for most purposes and our children's case managers for most purposes. When things get really complex, and when people's abilities to make judgments are impaired, it is necessary to have professional intervention and participation. So we have a continuum of need in the case management area.

The UAP's will speak for themselves. I want only to say that from the point of view of equity, your point was very well-made in your questioning of Dr. McFadden, that we have some geographical areas in the country that really do not have adequate access to the resources in professional training and technical assistance and model programs that are reported by the UAP's, and we would certainly urge that that be addressed, and obviously it cannot be addressed with out additional funding if the present UAP's are to be appropriately protected and supported in their current activities.

Finally I want to say a word or two about projects, since they don't have their own spokesperson on the later panel, Projects of National Significance. We would like very much to see those focused in on issues such as Senator Durenberger has raised.

Dr. Lakin is masquerading here as a consumer, a foster parent, but all of us know that the data that he and his colleagues have collected over the years have been extremely helpful to all of us in really indicating where we are going and how we are getting there.

Similarly, the economic information and the fiscal information that has been pulled together by Dr. David Braddock and his peers is very valuable to us.

It is extremely important that we have consistent continuity in the collection of data. I don't have time to tell you the details, but I can say that in 1981-82, when David Stockman was in charge of the budget, he destroyed quite a lot of the data-gathering capacity of the Federal agencies, and that the break in continuity in gathering secular data—that is to say, data over periods of time—in a consistent and aggregateable way has done a great disservice to our cause.

Finally, let me characterize this action here today as a consolidation and forward movement of something that you put in place in 1987. We have our work cut out for us to carry forward on the 1990 reports and all the components of the Act. We thank you for your very early consideration of this bill, and I trust that the reauthorization will be signed not later than October 30th, 1990.

Thank you.

Senator **Harkin**. I just hope that we can make this 20th anniversary a really good anniversary and make sure we do get the appropriate amount of funding for the programs and the UAP's. We'll have more to say about that. But Dr. Boggs, it is always nice to have you back, testifying, with your vast knowledge of this, and to listen to you talk about this without referring to notes—you just know this so well, and it is wonderful.

[The prepared statement of Dr. Boggs follows:]

PREPARED STATEMENT OF THE CONSORTIUM FOR CITIZENS WITH DISABILITIES
ELIZABETH M. BOGGS, Ph.D., ON BEHALF OF

My name is Elizabeth Boggs and it is my pleasure to testify on behalf of the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. I have had many years of close association with the concept of developmental disabilities and with the four programs authorized by this Act. I have served on the New Jersey Developmental Disabilities Council since its inception and chaired the first National Council on Developmental Disabilities.

In the late sixties, a small group of national organizations interested in meeting the needs of people with severe disabilities originating in early life were the moving force behind the first Developmental Disabilities Act of 1970. This group, which became the Consortium for Citizens with Devlopmental Disabilities, (CCDD) is now the Consortium for Citizens with Disabilities (CCD) consisting of more than 60 national organizations representing people with disabilities and their families, professionals, service providers, advocates and state government. The CCD works for the improvement of federal programs across a broad spectrum of needs including such programs as social security, vocational rehabilitation and education of the handicapped. Many of these organizations represent people with severe, life-long disabilities and have specific interest in the reauthorization of the Developmental Disabilities Act. The Developmental Disabilities Task Force of CCD has developed the document attached to this testimony which provides a comprehensive set of recommendations to improve the four Developmental Disabilities Act programs for the consideration of the Subcommittee on Disability Policy. My testimony will highlight the key issues in the attachment.

The Basic State Grant Program, the Protection and Advocacy System, the University Affiliated Programs and Projects of National Significance are critical elements in the creation of a comprehensive array of services, supports and assistance for those in our country with the severest disabilities. These recommendations are made in the context of overall satisfaction with the current direction of the law and accomplishments of the four programs.

LEARNING FROM THE PAST, ANTICIPATING AND PROVIDING FOR THE FUTURE

While the DD Act has always been ahead of the times, expressing new trends, pointing the way to emerging issues, staying on the cutting edge and in the vangaurd of "consumerism" in the field, the amendments of 1987 added several new and particularly exciting initiatives which are propelling the DD Act into the 1990s. The CCD recommendations, therefore, seek to fine-tune these recent improvements and to further strengthen already effective programs.

In the six years since the purpose of the DD programs was refined to express the goals of independence, productivity and integration into the community for people with developmental disabilities, the field has been changing rapidly. As the buying power of specialized programs has been seriously depreciated, the DD programs have attempted to fill the widening gap between what people with developmental disabilities need and what is available. Considerable progress has been made in recent decades, yet old models persist in many public and private programs even though these have been found far too frequently, to thwart independence, productivity and integration into the community. In addition, some excellent programs are losing ground after initially encouraging trends. For example, in the National Consumer Survey, which you will hear more about in later testimony, we have discovered a strong indication that educational options are primarily limited to special classes (25.5%) and special day schools (29.1%) for more than 54% of the students with developmental disabilities in special education, in spite of the goal of education in settings which foster association of children with disabilities with their non disabled peers. (Later this spring, Congress will receive the nationwide results of the DD Councils' 1990 Reports in which dozens of federally-assisted programs have been evaluated for their effectiveness toward the goals of independence, productivity and integration. As part of this process, more than 14,000 people with disabilities and their families responded to the National Consumer Survey.) The experience of states in developing these findings undergirds many of CCD's recommendations.

Human services are under great strain and resources in the last decade have been pushed to the limit. The DD Councils have worked hard to influence the direction of publicly funded programs and have had a geat deal of success; however, they have also looked to the non-governmental sectors, private employers, community associations, and just ordinary neighbors to help to develop ways to meet people's needs and to achieve true community integration, allowing communities to receive the contributions of people with developmental disabilities first hand. This latter concept, expressed so well in the 1987 amendments, addressing the capabilities as well as needs of people with developmental disabilities, has been not only correct in terms of true community integration, but has been required, due to the resource reductions of the 80's. The concepts of independence, productivity and integration, appropriate goals for public programs, are expanding to include inter-dependence, contribution, participation and inclusion in every day life. The CCD recommendations attempt to enable the DD programs to encourage and support these concepts as well.

As we approach a new millenium, these next ten years will be critical for the design and delivery of services and other assistance to people with developmental disabilities. The 1984 and 1987 amendments to the DD Act have been gradually building the capacity of the DD programs to play a critical role in these activities. The 1990 Reports provide a foundation for informed for informed action on many fronts in preparation for integrated services and inclusive communities.

THE POWER OF LANGUAGE

The DD Act has, for many years, been a leader in teaching us how to speak and write about people with disabilities. The "people first" approach to language was first expressed in law in the DD Act, helping us all to think differently about people with disabilities - as people first - who happen to have disabilities, who need and want the same things that everyone wants in life. In addition, the way services are designed depends a great deal on how they are defined - that is, what they are intended to accomplish. When Councils advocate for family support, for example, the way this term is understood will determine what kind of support is provided and the method of provision. This is why the CCD recommendations take such care in revising definitions. We hope to work further with the Subcommittee on several of them.

Other language recommendations are made to reflect the results of the 1990 reports and to up-date concepts in the law.

DEVELOPMENTAL DISABILITIES COUNCILS - LEVERAGOMG RESOURCES AND

EMPOWERING INDIVIDUALS, FAMILIES AND COMMUNITIES

Shortly after the enactment of the first DD Act in the 1970's, it became clear that the Basic State Grant Program was not to become a federally financed service system for people with developmental disabilities. The dollars were simply not there. Congress redirected the program to one of advocating for and leveraging other sources of funds and the program has been exceedingly successful in doing this nationwide. You will hear in other testimony later today of some of the systems change successes of this small program. CCD recommendations aim to further improve the ability of DD Councils to perform these unique functions.

Councils are guided in their activities by priorities established by Congress, which emcompass "community living", "child development", "case management" and "employment" (a mandated priority.) There is also an opportunity to have a state priority that addresses unique situations which do not "fit" into the federal priority areas. This approach has worked very well and requires only one modification to keep pace with the current state of knowledge. This, the major programmatic suggestion by CCD, is based upon the results of Councils 1990 Reports and recommends an expansion of the federal priority area of case management.

In 1987 Congress mandated that all Councils develop reports on a broad range of issues which have been submitted to their governors and state legislatures and the Secretary of Health and Human Services in January 1990. Councils were directed to study not only the effectiveness of federally-assisted and state-financed programs but to determine how satisfied people with disabilities are with what they receive and to identify groups which are unserved and underserved. These "snap-shots" formed the basis of a "Report Card" on the status of services in the 56 states and territories and resulted in a series of recommendations which Congress will be receiving later this spring.

Councils have found that solving the problems of program ineffectiveness, consumer dissatisfaction and serving the unserved and underserved requires federal leadership including modification of a federal priority area to focus activities on such solutions. There are three inter-related problems to be solved. Many programs exclude people who need assistance based on eligibility restrictions. These restrictions vary from program to program and individuals and families must navigate a complex maze of laws, regulations, procedures and multiple tests of eligibility. As one mother interviewed in the National Consumer Survey said: "I had to make $300 worth of phone calls to dozens of different agencies to find out my son wasn't eligible for anything!" Addressing these eligibility barriers is critical.

This mother's sentiments also point out that many people don't know how to go about finding what services do exist. There are variations from community to community, county to county, and the roles and responsibilities of agencies are confusing or unknown. Casemanagement and information and referral, pivotal elements to help coordinate and locate services for people, are fragmented, not comprehensive in terms of state-wideness, provided by a multitude of agencies with different mandates, and have little apparent structure. From the point of view of the "customer", there seems to be no coherence or organization at the local level. People are forced to struggle to get into the system, even if they are eligible.

Also, once people are served in the community, it can be difficult to monitor quality in dispersed settings in regular neighborhoods and to ensure that resources will continue to be available to support those services. Citizens with disabilities and their families, as well as the general public, need to be involved in positive ways to create inclusive communities. They need help in organizing themselves on the local level.

Solving these problems includes, but goes beyond, case management and CCD recommends a federal priority to encompass these activities.

Some planning and administrative recommendations are made to ensure the overall effectiveness of the DD Councils themselves and their staffs, increasing their ability to advocate without inappropriate interference. These recommendations include: (1) authorizing the Council to direct basic state grant expenditures as intended supports activities which meet the goals of their state plan, (2) clarifying that Council staff is empowered to act only on behalf of the Council, implementing its decisions rather than being assigned extraneous tasks, (3) clarifying matching rate requirements for various activities, (4) up-dating the state plan requirements to include the findings of the 1990 reports, (5) allowing Councils to recommend further gubernatorial review of the placement of Councils within state government if the current designated state agency thwart the systems advocacy role of the Council, (6) ensuring that vacancies on the Council are filled to enable the Council to carry out its mandated functions.

The creativity of Councils in leveraging the limited funds available under this program to expand the array of services and supports available to individuals and families has demonstrated that a great deal can be done with very little; however, the ever-increasing responsibilities of this program, as well as the heightened expectations for program outcomes, requires that in FY 1991 we begin rebuilding the purchasing power of the Basic State

Grant Program in order to implement the many findings of their 1990 Reports. In 1987 Congress asked Councils to educate policy-makers at the state and federal levels about what needs to be done to ensure independence, productivity and integration into the community for people with developmental disabilities. They have completed this job and Congress will soon receive their findings. These Reports have created community expectations that now that we know what to do in each state and that nationally, it will be done. Congress is strongly urged to heed the CCD recommendations regarding authorization of appropriations for the Basic State Grant Program and to follow-through with strong advocacy for actual appropriations for FY 1991.

PROTECTION AND ADVOCACY SYSTEMS

Protection and Advocacy testimony for the DD Act Reauthorization Senate Subcommittee on Disability Policy. The P&A for persons with developmental disabilities is presently in its twelfth full year of operation. In FY 1989, the P&A system served 70,508 individuals including persons with mental retardation, cerebral palsy, epilepsy, spina bifida, learning disabilities, multiple sclerosis, mental illness plus many other disabilities. The P&A system continues to provide legal representation to persons with developmental disabilities in a variety of problem areas including abuse and neglect, special education, guardianship, housing, rights violations, transportation and rehabilitation.

One of the major reasons for the success of the P&A systems has been the underlying principle within the system of conflict-free advocacy and independence. The Governor of each state has the authority to designate an agency to serve as the P&A. However, the Governor must assure that the agency is independent ofservice providers and able to pursue legal, administrative and other appropriate remedies without interference.

The Governor may not redesignate the agency without good cause. However, two serious problems have arisen in several states which have threatened the ability of the P&A to function independently and appropriately represent its clients. Due to the absence of a clear process for redesignation, several governors have not properly communicated with the agency about problems they were having with the program and did not give proper notice to the disability community for their input. A clear process for redesignation by governors must be established in the statute to assure that the agencies are not unduly pressured to ignore the needs of their clients.

Furthermore, several states have governing boards that are appointed by governors. This practice creates a perception of control by the governor's that was not intended by Congress. The non-profit P&A agency governing boards should not be appointed by governors or their designees and service providers should not be allowed to serve on those boards. This practice has caused some interference with the aggressive pursuit of the necessaryremedies for serious situations within the state. Equally important, however, is the need to demonstrate to persons with disabilities that the P&A is indeed independent and able to represent their interests without undue control form the very agencies from which the individual may be seeking redress of a grievance. Several of the recommendations in CCD position statements (attached) address this issue and should be enacted.

Clients who reside in large state facilities are often the least served clients in the system. Unfortunately, due to lack of resources, the P&A agency must make hard choices of whom to serve, which can result in failure to reach out to this population. When P&A's do try to monitor the conditions in these large facilities, they often meet the resistance of administrators and staff who inappropriately claim the right of confidentiality for the clients who need the services of an advocate.

In the past year, several states have experienced difficulty in reaching clients for whom the agency has reason to believe that abuse and neglect may be occurring. In cases where the client has a guardian, existing law requires that the P&A not become involved if the guardian refuses the assistance proffered by the

P&A. In many states, the institution are so removed from populated areas, that the P&A may have no contact or knowledge of the conditions in those facilities. P&A's must have clear authority to reach clients who are not able to contact the P&A themselves. Claims of protecting client confidentiality, presence of a guardian, alleged disruption of the therapeutic environment cannot be used to prevent protection and advocacy service from being available to these vulnerable persons. The CCD position document contains recommendations to address the access problems currently being experienced by the P&A system including providing access for P&A for the developmentally disabled consistent with the access authority of the P&A for Mentally Ill Individuals.

The lack of adequate financial resources continues to be the major barrier to providing the full range of protection and advocacy services to person with developmental disabilities. Also the recent new civil rights protection s provided by the Congress for person with disabilities will require extensive outreach education and enforcement so that the full potential of these laws are realized. The Nursing Home Reform Act, Fair Housing Act, Civil Rights Restoration Act, and the Air Carrier Access Act and its regulations have increased the demands on the P&A's for services.

The imminent passage of the Americans with Disabilities Act and its potential for fully integrating persons with all disabilities into the mainstream of American society will also dramatically increase the pressure for advocacy services. Congress must adequately fund the Protection and Advocacy System, or risk providing empty promises of full access to the rights and benefits of our country to person with disabilities.

UNIVERSITY AFFILIATED PROGRAMS

There are now 48 University Affiliated Programs (UAP's) funded by ADD in 44 states. The first twenty were established in the late 1960's under very different priorities than now prevail; these earlier stalwarts have made a successful transition from the campus-bound, pediatrically oriented facilities of that period to the well rounded community resources they are today. The second and third generations of UAP's born in the 70's and 80's have added diversity and vitality to the entire movement.

We have learned that to be fully effective in upholding high standards of hands-on service delivery based on contemporary criteria, UAP's must have a well defined primary catchment area that has a rational integrity. The initial geographic imbalance that has been discussed at previous hearings is still not entirely rectified. We hope, therefore, that in its reauthorization language the Committee will continue to encourage ADD to apply principles of "equal access" to this program. At the same time care must be taken to assure the viability of the existing centers. Clearly, additional funds are needed to ensure that every state in the union will enjoy the benefits of a UAP before the end of the century.

As the Committee knows, the UAP programs are multifaceted; some directly provide tertiary clinical services or other exemplary programs that not only serve individuals, but can also enhance the experience of advanced students in the various professions whose skills are essential to the realization of goals for children and adults with developmental disabilities; others carry out their responsibilities for renewing the cadre of professionals trained to work in interdisciplinary teams through university-based training programs that are linked to appropriate community based services. All UAP's are invested in providing technical assistance to state agencies, community providers, parents and people with disabilities, individually and collectively. Among them UAP's manifest a wide range of expertise that can be put at the disposal of the system as a whole as well as to serving the people of their respective primary catchment areas.

By the way of examples of the richness of resources that UAP's bring to the system we can cite the community support services of the Kennedy Institute at Johns Hopkins University in Baltimore, the leadership in assistive technology in the UAP's located in Iowa, Utah, Missouri, New Jersey, Alabama and Wisconsin, and the nationally significant public policy studies conducted under the auspices of UAP's in Illinois, Minnesota and Massachusetts. The Kennedy Institute is a licensed child placement agency that directly administers a large foster care program for children with developmental disabilities, including those with the most complex impairments. Operating through its Community Development Division, this UAP provides intensive training for foster parents and an extensive array of in-home support services including occupational therapy, and nutrition as well as case management. The products of the policy centers in documenting the demographic and fiscal changes associated with "communitization" and the success of our employment initiatives are well known to the Committee.

As we enter the 1990's, the UAP's are rising to meet new challenges. Eleven UAP's are currently providing habilitative services in six major metropolitan areas to infants exposed to drugs. We now know that prenatal exposure to this form of cocaine puts a child at great risk of developing cognitive deficits. In addition, congenital AIDS is a growing cause of severe childhood disability; 90% of children with AIDS will manifest mental retardation or cerebral palsy. We are proud that the UAP network has been in the forefront of recognizing and addressing these problems; it now provides services to over one third of the nationally identified pediatric AIDS population, with the pioneer Rose F. Kennedy Center in the Bronx, New York providing services to over 200 of these infants.

While the direct clinical services provided by UAP's (a total of 72,500 having been served last year), are of critical importance, the principal mandate and raison d'etre of UAP's is the preparation of personnel for the field. Dozens of professional disciplines, including law, public administration, social research, theology, labor management, architecture, and economics, as well as the traditional educational, health and human services disciplines, must be brought to bear on the issues at hand. Each must understand the adaptations and accommodations that disability entails and all must learn to work effectively in interdisciplinary collaboration. Each UAP plays an individually defined role in this complex mission.

Again, however, innovation and new initiatives must be coupled with assuring that the basic manpower needs of an expanding service system are met. Without trained allied health professionals, our nation cannot provide appropriate early intervention services to infants and toddlers with disabilities. Without well prepared direct care staff, we cannot expect parents to have confidence in a system of community-based living arrangements. Without people of specialized social work skills, we cannot put in place effective case management services that support individuals and families in their efforts to take control of their own lives.

Growing waiting lists for services and the 1990 reports' documentation of unserved and underserved populations in all categories of disability clearly show that the absolute numbers of people in need are increasing relative to twenty years ago. It follows that we need many new recruits to the traditional disciplines in health, education, social work, and rehabilitation; once recruited they must be imbued with positive attitudes toward the potential of people with disabilities and armed with "state of the art" know-how in bringing that potential to realization. Only with such commitment can people with developmental disabilities come to enjoy greater independence, productivity and participation This is the role that UAP's must continue to be empowered to play.

PROJECTS OF NATIONAL SIGNIFICANCE

The traditional pattern for programs of federal assistance to states in carrying out a national service agenda includes a formula grant to each state coupled with a discretionary grants authority or authorities in the corresponding federal agency to engage in capacity building activities to support the main mission. The UAP program serves this purpose with respect to the preparation of professional personnel and - to some extent- technical assistance. The core grants to UAP's do not, however, adequately cover the needs for "R & D". The authority under

Section 162 for ADD to make grants for Projects of National Significance services this purpose; it permits such grants to be made to any public or non-profit entity specifically qualified to contribute to ADD's stated priorities. In 1980, the funding under this authority exceeded $20 million. Present levels, however, represent a cut of 85% in this account compared to the 1982 budget. It is therefore necessary to target these funds narrowly on critical needs of the programs these grants are intended to support and enhance.

We know that changes are taking place very rapidly in our system and we need to know what is happening in "real time." Twenty five years ago the data gathering capacity of the Biometrics Branch of the National Institute of Mental Health was partially destroyed without generation of a comparable base for the then Division of Mental Retardation. Partly as a result of this and partly because we were still collecting and reporting data manually, important changes were often undetected for several years after they occurred. For example, when in 1971 President Nixon declared his priority for reducing by one-third the population of public institutions for people with mental retardation, we did not have clear evidence that the turn down had already started in 1967. Since then we have acquiried the technology to accelerate both the collection and analysis of such data, but its usefulness will be much diminished unless it is promptly and consistently applied in a system designed to be maintained over decades. CCD is therefore proposing that support for the three documentation systems developed with ADD support (relative to employment, residential services utilization and state/federal expenditures supporting the target population) become a permanent part of the special projects authority. You need these data; state agencies need these data and Councils need these data, both on a state-specific and nationally aggregatable basis.

In addition, CCD is recommending that further analysis of the national consumer survey data stemming from the 1990 Report by supported on an ongoing basis. This the first time that such a survey of our population has ever been undertaken. Surely it will take years to fully benefit from the huge amount of data currently available. From a public policy standpoint, it makes sense to support continuing studies of the survey responses and related material to help guide future legislation as well as specific programmatic initiatives.

Finally, CCD strongly supports the pursuit of a nationwide personnel needs assessment. The last credible study on this issue took place in the mid-1970's. There is a great need to identify where the personnel gaps are in our existing service systems so that we, as a Nation, can make informed judgments on were to invest very limited training resources.

SUMMARY

The community of people interested in or affected by developmental disability has been fortunate in its congressional champions. We have worked hard to merit the strong support that we have received from this Committee from its earliest days, and wish to acknowledge our debt to all the members of the Committee on Disability Policy of both parties. In particular, we express our warmest appreciation to Chairman Harkin for his understanding of the issues and his advocacy, as expressed in the Senate passage of the Americans with Disability Act and now for timely scheduling of Senate consideration of the reauthorization of this unique legislation. We look forward to another memorable 6 years.

Senator **Harkin**. Before we get into the questions, we'll just go down the line, and I will recognize Dr. Lakin, who is masquerading as a consumer.

Dr. Lakin is Director of Research and Information for the Minnesota University Affiliated Program and is nationally-known for his research regarding community and residential services for persons with mental retardation and developmental disabilities. His program at the University of Minnesota receives a grant under the Projects of National Significance Program to provide ongoing data collection of annual statistics on residential services on a State-by-State basis.

Again, welcome to the subcommittee, and please proceed.

Dr. **Lakin**. Thank you, Mr. Chairman.

I also want to thank Senator Durenberger for his kind, generous, and probably overstated introduction a little earlier.

Thanks for the opportunity to be here this morning.

I want to join everyone else in the room in thanking the subcommittee for your real commitments to full citizenship for all persons with disabilities. As a native Iowan and now a "naturalized" Minnesotan, I am particularly proud of the efforts of you, Mr. Chairman, and of course, Senator Durenberger in this area.

Senator **Harkin**. You've got all your bases covered.

Dr. **Lakin**. The DD Act is an important part of this national commitment to folks with disabilities. I think it is real easy for people here in Washington to under-estimate the importance of the DD Act. It really has a power that goes far beyond its Federal budget, and largely that power is vested in its ideals and the people who share those ideals, who are brought together through the programs of the DD Act.

Clearly, the DD Act is the most visible commitment our society makes to its citizens with developmental disabilities, and in many ways it has become a banner for a national movement of inclusion in this country.

I have provided the members of the panel with a packet of some materials that our DD Act programs in Minnesota have put together, and I think they reflect our efforts toward the same end to which the Act is committed and to which this subcommittee has been committed.

There are so many wonderful ideals and attractive programs in the DD Act—I have tried to make a few observations about some of them in my written statement. But the ultimate value of the DD Act is found in the lives of the people who are affected by it.

In my written statement, I tried to trace such impacts in the life of one young girl and her family. About two years ago, a young girl named "Jamie" came to be part of our family. It was her second long-term stay with us, but I am confident today it was her last.

Jamie came to live with us only after her parents had exhausted themselves, and being uninsured, had exhausted all their financial resources on medical services and other efforts to get help for Jamie.

You cannot imagine the pain and the self-doubt that went into their decision to place Jamie in a foster home—but with support, Jamie's parents have never given up. Jamie came to live with us, but her parents always remained her primary advocates. They received ongoing support and representation from our Protection and Advocacy staff. With P&A staff by her side all the way, they secured a placement for Jamie in a regular public school where Jamie spent halfdays in a regular classroom.

School integration is a growing practice in Minnesota; it is one that is advocated for by all our DD Act programs, and it is one that is supported by a statewide technical assistance project run out of our UAP.

Jamie's parents also became participants in a program called "Partners in Policymaking". This is a program that teachers parents and consumers to be effective self-advocates. It was the brainstorm of our State DD Council Executive Director, Colleen Wick, and it is a nationally recognized program today. Because of their participation, today Jamie's parents are not only very effective advocates for Jamie and themselves but literally for thousands of other Minnesotans with disabilities. In time, Jamie's parents began to work with lawyers of our P&A on a plan that would bring Jamie home. That plan used Medicaid home and community-based services to support Jamie and her family.

All three DD Act programs in Minnesota have been very active in promoting the use of that program to support families.

Assistance was also provided by the P&A in developing an individual education plan for Jamie for her return to her home district. This time, the plan didn't call for just half a day of integrated education; it called for all day. And today Jamie is home. She goes to a regular school, on a regular bus. She attends a regular classroom with the support of an aide. She lives in her own house with her own family, with needed family supports through the Medicaid waiver.

Her family receives assistance with Jamie's extensive medical costs through the TEFRA option, which provides medical assistance to children with disabilities who are living at home.

All of these services are ones that all three of our DD Act programs have worked hard for in Minnesota. Jamie still spends every other weekend with us. When she visits, she always attends a pottery class on Saturday. It is not a pottery class for kids with disabilities; it is just a pottery class for the neighborhood kids. It is another example of the kind of integrated recreation programs promoted in Minnesota park and recreation systems and other places through the work of people at our UAP.

So Jamie has grown up a lot like other kids in Minnesota. She is living in the same kind of home, going to the same schools, doing the same kinds of things. No one knows what adulthood promises her, but I have some general guesses. The next time Jamie leaves home, it is going to be as a young adult. She will go to a new home in the same community she is growing up in. She will remain close to her family and friends. This is much surer today thanks to recent legislation in Minnesota which will effectively close our State institutions over the next nine years. Our DD Act programs played an active role in promoting and negotiating that bold and positive step by our State legislature. These same programs are now all helping to make that plan work through planning, through training, through technical assistance, through advocacy, and through research and demonstration projects.

Jamie's future is also going to include a useful job with pay, the kind that people at our UAP are helping people establish all across the State.

In short, I have seen DD Act programs make a big difference in the lives of people. That difference derives in part from the funding of the DD Act, but it is just as much a product of the spirit and the national goals that the DD Act articulates for all of us.

Again, we all thank the subcommittee for its commitment to the rights of people with disabilities, and of course, I hope we will see reauthorization of the DD Act as an important part of that commitment.

Thank you.

Senator HARKIN. Thank you, Dr. Lakin.

[The prepared statement of Dr. Lakin follows:]

PREPARED STATEMENT OF K. CHARLIE LAKIN

I greatly appreciate the invitation to submit this statement for the proceedings of the Subcommittee's hearing on reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act. I want to thank the Subcommittee for its steadfast commitment to assuring the full rights of citizenship to all persons with disabilities. As Senator Durenberger noted in the floor debate on the Americans with Disabilities Act last September, "People with disabilities remain the only major segment of our society who can be outrightly discriminated against." Soon, we can now hope, such discrimination will be illegal. Although its full elimination will remain a challenge even for future generations, already this decade promises to be one of tremendous importance to people with disabilities, including those with developmental disabilities. Reauthorization of the DD Act will play a key role in this critical decade in our society's evolving appreciation of the rights, the potential and the contributions of citizens who have disabilities.

It's easy for people here in Washington to underestimate the importance of the DD Act, after all the total federal expenditures for DD Act programs in 1988 were only about 2% of federal expenditures for persons with developmental disabilities under Title XIX of Medicaid alone. In 1988 federal expenditures for the ICF-MR program in just New York State were 6 times as great as the total appropriation for all DD Act programs. But the power in the DD Act has not been in its budget. The power is in its ideals, and the people sharing them, who are brought together in common purpose through the Act. The Act is by far the most visible and most widely noted statement of the goals that the nation holds for its citizens with developmental disabilities. In the Act's statement of purpose, those of us in the field find our own individual and collective purpose, that is to assist people with developmental disabilities to achieve their maximum potential through increased independence, increased productivity and increased integration into the communities of this nation.

The DD Act is the banner legislation of a national movement of inclusion in this country. That movement includes people with developmental disabilities and their families, it includes people who provide services and supports, it includes advocates and academics, and as you reaffirm with reauthorization of the Act each three years, it includes the Congress of the United States. It also includes in important ways the staff of the Administration on Developmental Disabilities, which over the years has effectively promoted the purposes of the Act through its initiatives. Through the Act, the Administration on Developmental Disabilities has been an active participant in preaching what Bob Williams calls "the Gospel of the Possible."

Since 1963 the DD Act has been an evolving statement of our nation's commitment to its citizens with developmental disabilities. It has set the standard by which we guide and evaluate our general efforts and our specific programs in behalf of persons with developmental disabilities. As we have evolved as a society, so too the purpose, programs and language of the Act, with each reauthorization, have reflected greater respect and recognition for the rights, potential, accomplishments and aspirations of citizens with developmental disabilities. As this new bill is shaped, you must once again take stock of where we are and where we can get as a nation. I urge you to consider carefully the extent to which the words used, the goals set, and the ideals communicated contribute to an improved national vision of what life can be and should be for citizens with developmental disabilities.

There is so much that can be said about the past and potential provisions of this important document, and their effects on the lives of people with developmental disabilities. In the allotted length of this written statement I can touch briefly on only a few.

General Provisions

The Bill of Rights. I believe that in 1990 it is important for the Subcommittee to revisit the Bill of Rights portion of the DD Act. The rights articulated in the Act were last revised in 1984. Much has changed since then in professional and societal views of the rights, dignity and proper respect of people with developmental disabilities, in no small measure because of the work of the Subcommittee. Much has also been learned about appropriate and effective services. The stated rights of people with developmental disabilities should reflect this evolving understanding. The rights as currently expressed are too general to provide assurances. For this to be a true Bill of Rights it must specially address areas in which people with developmental disabilities experience the most frequent and culturally atypical deprivation of basic rights. One very visible of such areas is the use of aversive (punishing) procedures, but it is by no means the only one. A much more specific statement is needed if this bill is expected to actually set standards for recognition of real rights for people with developmental disabilities, rights that can be and will be protected. I would urge the Subcommittee to place these rights in high prominence at the beginning of the Act, just as our nation's first lawmakers placed our rights clearly and inviolably as the cornerstone of the laws of the United States.

Congressional Finding Regarding Prevalence of Developmental Disabilities. Estimates from the National Health Interview Survey and other sources indicate that there are about 35 million Americans who experience limitations in major life activities. Various estimates would suggest that somewhere in a range around 10% of these individuals might exhibit developmental disabilities. However, it is important to note that there has never been a national study of the prevalence of developmental disabilities, nor has there ever been within any other national survey inclusion of data elements that would permit estimation of the prevalence of developmental disabilities as defined in the DD Act. This is not a problem of particular importance to the Act itself. However, the impact of the Act is broad. A number of recent policy proposals have included the definition of developmental disabilities in this Act as standard for program eligibility. The lack of national statistics on the population of people meeting that definition makes it essentially guesswork to estimate the number or characteristics of people who might be eligible to participate in certain proposed programs. Such difficulties are likely to increase. The definition of developmental disabilities provides a meaningful description of people who need support because of functional limitations. Therefore, it is naturally attractive as a standard for defining who would be eligible for various types of support. Last month the Assistant Secretary for Planning and Evaluation received the final report of a design project for a National Survey of Persons with Developmental Disabilities. The Subcommittee might wish to consider whether this Act might be the vehicle for supporting such a study.

Planning Councils and Protection and Advocacy

My involvement with State Planning Councils and State Protection and Advocacy (P & A) Systems is primarily one of providing technical/informational assistance. However, I have seen first hand the many influences of my state's DD Act programs in the lives of children with developmental disabilities for whom my family and I have cared. Perhaps I can best communicate those influences by taking one family and noting how different DD Act programs have been evident in the lives of its members.

About two years ago a girl named Jamie joined our family for a year. As Jamie's mother wrote to members of the Subcommittee on Health at the time of March 1988 hearings on Medicaid reform, "After exhausting every avenue we knew of to get help and realizing we could no longer cope with the financial, physical and emotional stress, we had to place Jamie in a foster home . . .'[4] Although Jamie lived at our house, with the support of her case manager, a participant in a joint UAP and Minnesota Department of Human Services training, Jamie's parents always remained Jamie's parental representatives to all social service and educational agencies. With assistance from Ann Henry of our dynamic Protection and Advocacy agency, Jamie's parents sought and secured her placement in a normal school, where Jamie spent half days in a regular classroom. School integration is growing practice in Minnesota with strong advocacy from all our DD Act programs, including major technical assistance projects led by Jennifer York and Terri Vandercook of our UAP. Jamie's mother became an early participant in our DD Council's Partners in Policymaking. This is a nationally recognized training program of individual and collective self-advocacy for parents and consumers developed by Colleen Wieck, the creative and tireless Executive Director of our State DD Council. Later Jamie's dad also became a participant, and today promotes change from a position on the Government Affairs Committee of the Association for Retarded Citizens of Hennepin County. As their knowledge, skills and confidence increased Jamie's parents became effective advocates for Jamie and themselves, but also for others. They began to develop with lawyers from our P & A a plan that would bring Jamie home. With that assistance a plan was developed that would use a Medicaid Home and Community-based Services waiver package to support Jamie and her family. All three DD Act programs have been active and effective in Minnesota and beyond in promoting and evaluating the use of that program to support children and adults with developmental disabilities in community settings. Assistance was also provided by P & A staff in developing an Individual Education Plan for Jamie's return to her home school district. This plan was not for half a day of integrated education, as when Jamie lived with us, but for a full day.

Today Jamie's home. She goes to a regular school on a regular bus, and attends a regular classroom with the support of an aide. She lives in her own house with her own family, with needed family supports through the Medicaid waiver. Her family receives assistance with Jamie's extensive medical costs through the TEFRA option to provide Medicaid services to disabled children and youth living at home, to which Minnesota subscribes in no small part because of advocacy from our State Planning Agency and our P & A. Jamie spends every other weekend with us in a respite care program, another service obtained with P & A assistance and provided to hundreds of Minnesota families after years of advocacy and planning from our State DD Act programs. When Jamie visits us she almost never misses pottery class on Saturday. It's not pottery for children with developmental disabilities. It's just a pottery class for children, and another example of the kind of integrated recreation program fostered in Minneapolis Park Board Programs and elsewhere by the work of Stuart Schleien of our UAP. The only time Jamie misses the class is when she has better offers, like the classmate's birthday party she attended a couple of weekends ago; not a classmate with handicaps, just a classmate.

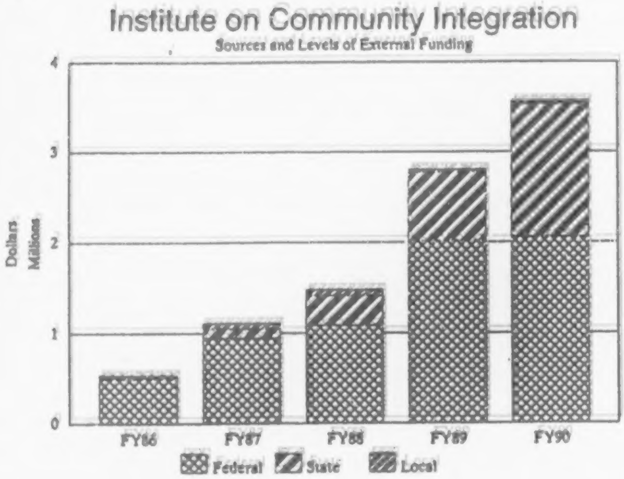
So Jamie is growing up, like other kids in Minnesota, going to the same schools and doing the same things. No one knows what adulthood promises, but it's pretty easy to make some general guesses. The next time Jamie leaves home it will be as a young adult to a new home in the same community in which she's growing up, close to family and friends. This has been made much surer for all Minnesotans by recent Minnesota legislation which will effectively close our state institutions by the end of the Century. All three DD Act programs played an active and effective role in encouraging the Minnesota legislature to take that bold and positive step. These same programs are now all actively helping to making it work, through training, planning and development activities, working along with committed and well-trained advocates like Jamie's parents. Jamie's future will surely include a useful job with pay, like the ones David Johnson of our UAP helps develop and support. Importantly DD Act programs in Minnesota are working hard to insure that the results that have been seen in the life of Jamie and her family will not have to be precipitated by the trauma of out-of-home placement, but will be available to families when they are needed (something to which the Subcommittee might choose to speak to as it considers the rights of children with developmental disabilities). In summary, in my direct experience the Minnesota DD Council and the P & A are making a difference, sometimes a profound difference in the lives of individuals with developmental disabilities and their families.

University Affiliated Programs

Core program support. Over the years I've had the opportunity to view the UAP program in the early 1980s as an independent program reviewer, and since 1985 as a UAP Research Director. I prefer the latter to the former, so I'm grateful to the Subcommittee and to Congress for opening up the program to states that were previously without a UAP. But this effort has not yet included all states. Unlike most federally-funded centers with research, training and service components, UAPs have a clear intra-state mandate. States without UAPs are denied a resource of considerable potential in furthering the goals of the DD Act that are available to the vast majority of states. I would hope Congress would commit to the ultimate establishment of UAPs in all states with this reauthorization.

As a matter of stressing the possible significance of a UAP in developing important resources within a state, I would like to share some statistics from ours. We call the Minnesota UAP the Institute on Community Integration which fairly summarizes that to which we are committed. Figure 1 shows the changes in our amounts and sources of funding since 1986, our first year as a full UAP. Obviously we have grown tremendously in the past 5 years. But more critical to our mission as a UAP is how we've grown. In 1986 over 90% of our funds were federal UAP and research dollars, the latter primarily in residential services. Today, federal monies make up less than 60% of our funding. For every federal UAP dollar we now access $7.50 from state and local sources. The University of Minnesota alone contributes more to our program than the $200,000 we receive from our core UAP grant. Residential services still remains one focus of the Institute, but now comprises just a small part of our total budget and activities as our UAP is evident in almost all areas of community life.

Figure 1



For us, UAP funds have been leveraging dollars, the value of which to program development has far exceeded their nominal worth. UAP funding over the past few years has allowed us, with dynamic and resourceful leadership from Bob Bruininks, to begin initiatives in new priority areas as we seek alternative stable funding. But it is not just that we have been assisted by this funding to rapidly increase our total support, it is that we have been able to do so in areas that we feel we need to enter. What has changed most dramatically is not the number of staff members coming in our door each morning, but the number going out the door throughout the day to provide training, technical assistance and consultation to community agencies. The second most dramatic change has been our huge increase in nontechnical publications for community audiences, especially people with developmental disabilities, families, service providers, and governmental officials. We simply would not have been able to do this nearly as rapidly or as well (if at all) without the UAP core funding. Of course, should Congress find reason to increase UAP core grants, we have no shortage of identified needs and opportunities we would like to pursue.

Training grants. Movement of the services and supports out of the large segregated centers where both people with developmental disabilities and services for them were once congregated has brought many challenges. One of the most important is meeting the training needs of people who provide services and supports, as they like the people they serve, are also dispersed throughout our communities. Each year as thousands of additional persons with developmental disabilities are served in community settings that challenge increases. Prior to the reauthorization of the DD Act in 1987 a number of us in the UAP network developed concept papers regarding training initiatives needing to be carried out by UAPs. With support from the Consortium for Citizens with Disabilities and the Subcommittee, funding for training initiatives were included in the 1987 Act in three areas: early intervention, programs for elderly and aging individuals, and direct care personnel. The training initiatives have been important and productive. I believe they deserve to be continued in the reauthorization. I would urge two changes. First all UAPs, with required consultation with the State Planning Council and the State Mental Retardation/Developmental Disabilities program agency, should be able to choose independently the area of their training focus reflecting the most pressing need within their state, and not an arbitrary distribution of funds between the three priority areas. In the application for those funds states should be required to document how training needs were established and where the training fits into the total training picture within a state. Second I would urge further expanding of the training initiative to make funding available to all UAPs. There simply are no states without very significant training needs.

New initiatives and support projects. There are two areas of training that I would particularly urge the Subcommittee to consider adding to the reauthorization bill. The first is nonaversive/positive approaches to problem behavior. More and more of the people entering our community programs bring with them "behaviors" that present difficulties in community settings. Staff members in those settings need improved training in responding to the behavioral needs of these individuals. Punishment is easily practiced, but it teaches nothing. Worse, it is counter to the recognition of rights and dignity and persons with developmental disabilities which is the heart and soul of the DD Act. There is a developing, effective technology of positive behavior management that is replacing punishment in controlling problem behavior. Improved general practice in this area is essential to efforts to fulfill the promise of the Act. UAPs, as well as other training organizations, would benefit from support projects in positive behavior management that would provide them with training and technical assistance that they could then apply to their efforts to train others.

A second area of particular importance is the utilization of technology. UAPs are not likely for the most part to be heavy developers of technology, but they are often in the front lines in its application. UAPs would all benefit from a program of technical assistance in this area. This would involve technical training in areas like computer assisted communication and other electrical and mechanical devices, but would also include simple sharing ideas about applying existing technologies. Technology is often essential to integration, as exemplified by a boy named Roger in my son's neighborhood fifth-grade classroom. Roger has severe cerebral palsy, which requires him to use a voice synthesizer to communicate and a computer for most of his school work. But the support of integration should be the focus of UAP applications of technology. It is the integrated setting which determines the useful technology, as often as the technology determines what might be the opportunities for integration. This was pointed out to me when Roger joined my neighborhood baseball team. My initial goals were primarily to keep Roger involved with his peers outside of school and because Roger's parents were recent immigrants from Southeast Asia to teach Roger our national game. Our park director took no time at all to note that Roger could participate much more effectively with an assistive device. The Minneapolis Fire Department bought that device for our park and with it Roger became the best batting practice pitcher I've ever had (or been). The device was a pitching machine and I am convinced that I would never have thought of that myself. It was integration first that caused useful technology to be apparent. Integration and technology together unleash the tremendous creative and caring drivers of this society. UAPs will benefit in fulfilling their commitments to increasing independence, productivity and integration with projects of assistance and support in the applications of technology for integration. Such National Support Projects could be drawn from among the UAPs, or on a competitive basis from any center with the ability and expertise to provide the needed assistance.

Projects of National Significance

We at the University of Minnesota have participated in various Projects of National Significance under the DD Act. We presently operate the "residential services and supports" component of the Ongoing Data Collection System that was referred to in the 1987 Act. I think it's fair to say that our project is the primary and only continuous source of data on residential and related services for people with developmental disabilities. These data are used for policy and planning in virtually every state each year and find their way into the deliberations of many agencies and policy making bodies here in Washington. The Expenditure Analysis Project, at the Illinois UAP is another so-called "Project of National Significance" that few could deny fairly lives up to such a billing. So, too, will the Employment Statistics at the Boston Children's Hospital UAP. Such data collection projects are important within the reauthorization of the DD Act, because no federal agency other than ADD has a research program with its primary focus on people with developmental disabilities. Funding for research and data systems on developmental disabilities by other federal agencies can generally be characterized as inconsistent, discontinuous, inadequate and driven by administrative issues.

With that these initial Projects of National Significance producing needed data, I would like to suggest another area that is absolutely critical to the objectives of the DD Act. That area is personnel recruitment, utilization and retention. In this past decade there has been growing concern about personnel problems in community services. Staff turnover is extremely high by the standards of almost any industry, on average 50% or higher each year. To compound the serious problem of high staff turnover rates, is the increasing problem of recruitment, which can be expected to worsen as we near the Year 2000. One need not remind members of the Committee on Labor and Human Resources that the low birth rates of the 1960s and 1970s are destined to lead to serious labor shortages in the 1990s and beyond. The industries that will suffer most are those that pay the least, demand the most, and draw their personnel primarily from among young adults. Nothing better describes the paraprofessional labor force in community services. These problems are only exacerbated by the fact that direct care has traditionally been provided by women, and young women of the 1990s are likely to continue the trend toward seeking employment outside the traditional female occupations. Adding to the challenges is that fact that foster care programs, historically making up 15%-25% of community residential placements, and usually among the best integrated and least costly alternatives, are being affected by the changing American family, with fewer homes that are able or willing to provide foster care. These challenges will require effective efforts in recruitment from nontraditional employment pools. They will require much more attention to retaining staff. At present rates of growth in community service consumers, present staffing patterns and present rates of staff turnover, between the years 1990 and 2000 there will be a total of about 650,000-750,000 direct care personnel hired for community residences nationally. But barely one-in-ten will be hired to fill a new job; the rest will be replacements for people who quit. Our present training initiatives without attention to improving overall personnel practices are a little like pouring milk into a bucket with a hole. We need assistance in helping our states develop comprehensive personnel programs, ones which include training to be sure, but also assistance in personnel recruitment, retention and management practices. Other research areas of considerable merit have been recommended to the Subcommittee by the Consortium for Citizens with Disabilities.

Summary

The Developmental Disabilities Assistance and Bill of Rights Act has importance that far exceeds its level of funding. It supports programs that make a positive difference in the lives of people with developmental disabilities on a daily basis. It establishes the moral tone and basic standards for this society's response to its members with developmental disabilities. I urge the Subcommittee to support its reauthorization. I hope, too, that you will consider new ways that the provisions of this bill might further advance our national commitment and ability to promote the independence, productivity, integration and full rights of citizenship of persons with developmental disabilities. Finally, with gratitude for all you have done, I hope in all future matters before the Congress that Subcommittee members will continue to support and act on the high ideals and important purposes that are so clearly articulated for us all in this legislation.

Senator HARKIN. Now Ms. Roth, from Logan, UT, as I mentioned in the statement I read from Senator Hatch, is Director of a Northern Utah Independent Living Center. Ms. Roth contracted polio when she was 12, went on to finish high school, a bachelor of arts degree, and a master's degree in psychology. Helen was the founder of the Cache County Handicapped Action Council, and is the mother of a 32-year-old son.

We sure welcome you here today, Helen.

Ms. ROTH. Thank you. I almost felt like I was masquerading as a consumer.

I am very enthusiastic to have the opportunity to speak with you today on behalf of what I call "so-called developmental disabilities". So that you will know where I am coming form, I would like to tell you that a friend of mine and I sometimes joke with each other about the fact that we are glad we had polio before the labels and the special education tracks came into being to make the whole experience of having a disability very self-conscious and subject to the experts who know what is best for us. That is not in any way to degrade the types of legislation like the DD Act, but it is to say that many of us don't want others to have visions for us; we can have our own visions. We just simply want the opportunity to fulfill those visions.

Today I would like to focus on one particular aspect of the Act, although I think there are many things I would like to speak with you about. Time limits me to this one particular thing, and that is assistive technology.

Assistive technology is mentioned in the Act as nearly as I could tell just two times—one in which a definition is given, and the other in which it is just included in a listing under specialized services. And that is the extent of the references to it. It doesn't recognize the fact that assistive technology is a significant component in the lives of many people with disabilities that could enhance our opportunities for independence, productivity and full participation in society.

I'd like to give you a couple of examples. When I had polio many years ago, I was in the hospital for a year. When I came out, my folks were able to get me a big, clunky, wooden wheelchair that didn't go up and down steps, or fold up to go into a car. When the March of Dimes got me an Everest and Jennings sleek chair that could go up and down steps and go in the car, I was able to go back to school and join my classmates that I had left, and it was as totally liberating experience. I doubt that I ever would have been able to get on to Harvard had I not had that assistance at that time.

Another example: At the present time I have a friend with cerebral palsy who came on her own from South Carolina to Utah State. She is majoring in political science—or, I should say, she was majoring in political science. She had a power chair that she used somewhat like a car because there was no other transportation available. She goes out in the road with it—no curb cuts—and she goes long distances. That chair frequently broke down. She at times didn't have the money to repair it; consequently, she missed a lot of classes and flunked out of school. A hard worker, a bright girl—could not get the help she needed with her necessary assistive technology.

I would like to strongly urge you to give careful consideration to placing more emphasis on assistive technology in the Act, not just chairs, but the many newly-developed devices to help with mobility, with communication, with self-direction and with learning, for people who have sensory, physical and mental disabilities. I strongly recommend that you make funds available for research to help catch up assistive technology with the phenomenal advances in technology in general in this country.

I also urge you to appropriate funds—and I think it could be under the Special Projects part of the Act—for the purchase and repair of assistive technology for those who cannot afford it. Since Federal funds are short, I would like to make a suggestion as to possibly how that could be accomplished.

I think there is a possibility that seed money could be made available to the States to start private nonprofit foundations to hire staff that would be involved with generating corporate donations that could go for the purchase of assistive technology. I don't think that is going to happen without the appropriate for staff to organize those types of foundations, but I do think it is possible with some seed money.

I would like to thank you very much for this opportunity. There are about a dozen other things I'd really like to talk to you about—personal care attendants—that I consider in practice to be an exclusion of people that have disabilities other than mental retardation. I think that a lot of progress has been made, but I still think it is happening that the focus is narrower than it should be—a number of things like that that, if you would be interested in speaking about them, I would be happy to have questions.

I do thank you for this opportunity.

Senator HARKIN. Thank you, Ms. Roth, for being here and for that fine statement.

[The prepared statement of Ms. Roth follows:]

PREPARED STATEMENT OF HELEN COBURN ROTH

Chairman Harkin, senators and friends. I am honored to have the opportunity to speak with you on behalf of people with disabilities and to address the reauthorization of The Developmental Disabilities Assistance and Bill of Rights Act. I am Helen Coburn Roth from Logan, Utah. I had Polio in 1939 when I was 12 years old. After a long period of an active life, I am currently undergoing new limitationms because of Post Polio Syndrome or age or a combination of both.

I will focus my remarks on one primary issue: Assistive Technology. The Act provides a definition for Assistive Technology and then refers to it only one other time in a listing. Nowhere in tRe Act is it addressed as a significant component in the life of many people with disabilities, which of course, it is or, at least, should be.

After I first had Polio and came home after a year of hospitalization, my first wheelchair was a huge wooden one that could not be taken out of the house and, certainly couldn't be put into a car. I will never forget the liberation I felt when the March of Dimes helped me get an Everest and Jennings that a person could take down and pull up steps and that could be collapsed and put into the car. It meant that I could go back to school with the schoolmates I had left. As a matter of fact, my schoolmates were delighted to get me up and down the steps of the old Junior High we attended, because it meant that they could get out of class early to assist me before the halls got too crowded. I was fortunate! I remember one boy in my class who was brought to school and taken between classes in a wagon. He was teased and derided because of his disability. He probably had a disability other than Polio or he could have had a chair from the March of Dimes too. I'm sure it affected the rest of his life, just as my positive experience affected the rest of my life. That new chair meant liberation to me. I was not bound to a wheelchair, I was set free by it. I went on to do graduate work at Harvard, which I don't think ever would have been possible without the liberation of that wheelchair. This is just one small example out of one persons life that illustrates what assistive technology can mean. Another example may be meaningful. I have a friend who was attending Utah State University. She had Cerebral Palsy and was majoring in Political Science. She moved on her own from South Carolina to Utah and was doing pretty well with the help of a Personal Attendant. She began to have trouble with her power chair and didn't have the money to get it repaired each time it broke down. Even when she did have the money, she had to wait, sometimes a couple of days, for a vendor to pick it up and then wait a few more days while it was at the shop to be repaired. In the meantime, she was stuck in the dormitory and couldn't get to her classes. Her grades suffered to the extent that she flunked out of school. This, to me, is just intolerable. Here is a bright person, willing to put in the hard work to make herself independent and productive, but failing at it, so far, because of her financial limitations relative to an essential Assistive Device. I believe that the provision of Assistive Technology is the most cost effective way of augmenting the quality of life, the independence, the productivity, and the full participation in the community of many people with developmental disabilities. Wheelchairs are only one small aspect of the broad field of Assistive Technology. There are many other devices to assist people who have difficulty with mobility or other physical functions. There have been strides in high tech fields to provide devices that can assist people with vision problems, hearing problems and speech problems - -- devices that can enable and empower people to pursue their dreams under their own control.

Yet, the Act gives only a definition of Assistive Technology and in no way recognizes the integral role Assistive Technology can play in our lives. I would make two recommendations relative to Assistive Technology as it relates to the Act:

1. that money be appropriated for research and development of state-of-the-Art Assistive Technology, and
2. that money be appropriated for the actual purchase and repair of Assistive Technology for those people who cannot afford it.

Although the progress toward developing Assistive Technology has been significant over the past few years, it has in no way kept pace with the overall development of technology in our country. I don't believe it is cost effective for private companies to devote much capital to research and development, therefore I believe the government should appropriate money for it. The actual funding for Assistive Technology for individuals will be expensive, but not nearly as expensive as the consequences of not doing it. Many people could be more independent, more productive, and more fully a part of their communities if they could access the technology they need in order to enhance their capabilities.

I would like to touch briefly on one other issue: the perception by professionals, as well as the general public, that the Act refers only to people with mental retardation. Although, this segment of the population is significant and must not be neglected, some steps must be taken to reflect and make known to those people who administer the programs that the Act includes in its definition of disability, people with sensory, physical, and mental disabilities. Also, I personally believe that it is arbitrary and counterproductive to limit the Act to only those people whose disabilities occurred early in life.

Finally, I would like to congratulate you for the Developmental Disability Assistance and Bill of Rights Act as it currently stands. In 1987, you incorporated the basic philosophy of "independent living" and "control over one's life" as an essential part of the Act and you changed the language referring to people with disabilities and their capabilities in a very positive way. I highly commend you for this.

In summary, I urge you to give careful and close consideration to incorporating provisions for funding research and the purchase of Assistive Technology for people with disabilities and I ask you to take steps to see that people with sensory and mobility disabilities, as well as those with mental disabilities, are more equitably included in the programs administered under the Act.

Thank you very much for your time and attention.

Senator HARKIN. Again Dr. Boggs, I want to thank you for being back again and for all of the work you have done all the way from 1970 on, on this legislation.

I do not have a specific question for you, but I do have something I want to ask you in sort of a general vein, since you have been through this all the way from the beginning of this Act, and you have seen the advances that we have made in technology, the advances we have made in coordination, bringing together all the various aspects under an umbrella; this year, we have the Americans with Disabilities Act which is going to break down a lot more barriers to employment, communications, transportation, public accommodations.

What should we be looking at for the Nineties, what kind of problems are we going to come up with in the Nineties? If I'm sitting here in the year 2000—and I'm not certain about that, but if I am sitting here in the year 2000——

Dr. BOGGS. You are more certain than I am. [Laughter.]

Senator HARKIN. [continuing]. And I want to look back and think about the progress we made in the 1990s, what would I be looking back on? It is sort of a general question, but I'm just trying to get a handle on what you see coming down the road that we ought to really be anticipating.

Dr. BOGGS. Well, some years ago the President's Committee on Mental Retardation engaged a number of futurists to confer and think about those issues, and what they proposed of course covered a decade that has now already materialized, and I am not going to review that. But some of the notions or concepts that they used are worth mentioning.

We have movements which tend to run in waves. One of the caveats that futurists admonish us with is not to make extravagant linear projections; that every movement peaks and declines. And one of the thing that John Naisbitt noted in Mega-Trends is that even within a country like the United States where you can see some global trends, the different States often proceed idiosyncratically, and some are doing in a particular year what another State was basically addressing 15 or 20 years earlier, and vice versa, and that the national trend is somehow a composite of these local variations on the theme.

He mentioned, for example, that there are some bellwether States. He said that California started the salad bar idea, and that is now all over the country. California was also a State which was very early on into deinstitutionalization. It was moving people out faster, earlier, than many States. On the other hand, now California is confronted with a number of problems of quality control that States that have come on later have become aware of and are more readily able to anticipate and perhaps deal with.

Let me say what I see as the underlying trends that are not peculiar to this Act but are to the environment in which we will carry forward the activities of which this Act is a part.

You on this committee deal with disability policy, and this particular Act deals with a particular group of people who have certain things in common—namely, that they grew up with their disability, and that their education was affected by that, their economic status was affected by that, and so forth.

But we in the DD movement are all part of that larger movement which you have been espousing so vigorously in terms of the Americans with Disabilities Act. I have been rather heavily involved in that, too, and my observation is that it is very significant for the degree of its comprehensiveness and the degree to which people with a great variety of disabilities, people of all ages, people with mental disabilities, people with physical disabilities, people with chronic illnesses, have been brought under that umbrella and have seen themselves are part of a national civil rights movement and who are a very broadly-defined disadvantaged group.

That does not mean that within that group we don't have special needs for people with particular disabilities. People who are deaf have different needs than people who need wheelchairs, and there are different sections of the ADA that deal with some of those things. So we have had a very ambitious comprehensive approach in that Act, and all of us are very much indebted to this committee for getting that moved through the Senate so promptly.

But I think that that is significant in terms of the Developmental Disabilities Act. I don't think we want to particularly broaden its scope at this time, but I think that what is going to happen is that it will continue to make it possible for a minority within the disability movement to become more mainstreamed within that movement as well as in society as a whole.

I think we will see of necessity some breaking down of the distinctions between people who are and are not eligible for Medicaid, for example, which are based on economic as well as on definitional things—"unable to engage in substantial gainful activity"—is that really a meaningful definition that should determine the extent of need for services and for income support? We need to be able to blend, to move to cut down some of the arbitrary distinctions.

Senator Durenberger, I know the study you are talking about. Dr. Lakin was one of the contractors, and I was a member of the technical advisory group. It is a very important study which was generated in the office of the Assistant Secretary for Planning and Evaluation, and that's where it ought to go forward. The technical advisory group did include representation from a number of the Federal agencies that have bearing on this subject. It came about primarily because of the concern of defining the population that was the subject of the intermediate care facility for the mentally retarded legislation and hence the proposed Medicaid reform legislation that is in that area. So that mental retardation-related disorders became related to the question of how you define developmental disabilities.

Senator DURENBERGER. So then maybe what—pardon me for interrupting—but maybe John Chafee, Tom Harkin, and I ought to lean on the Secretary a little bit, to try to push that out?

Dr. BOGGS. Absolutely, absolutely. Please, all of you, lean on the Secretary in that regard. I know that Martin Gerry, the Assistant Secretary, is very well aware of the study, and of course, he is quite cognizant on disability issues. So I think if enabled to go forward, it will be done with considerable sophistication, and that is important.

One of the important things about that study is that it is so designed that it doesn't preconceive exactly what your definition of developmental disability will be. It will be a sort of two-stage affair in which it will filter out people who have some sort of impairment that appears to have originated relatively early in life, and then it will enable us to say, well, if you define developmental disabilities this way, this group would qualify; if you define it in another way, a somewhat different group would quality. That is very important for policy planning purposes. So I consider that a very important study, and anything that the Congress can do to show its interest in having the study actually done—what has been presented here is a design for doing it—would be helpful to us and to people who may not fall under anybody's particular definition.

In that connection, I do think that sometimes we do have a problem of people being eligible for services that they need. But I think that in the DD Act in particular, in the Act itself, we are interested in target populations. We are not interested in whether or not John Jones gets some money that happens to have been enacted under this legislation. We are interested in changing the accessibility of the environment so that John Jones and Jane Smith can both of them get in. And much of what we on the DD Councils do promotes the interests of people with disabilities generally rather than because people with developmental disabilities are part of that larger crowd.

To come back to your original question, Senator Harkin, one of the things that I think may happen, probably not this year, but maybe along about 1995, is that we will see a rapprochement between the DD enterprise and the independent living center legislation. I think it is extremely interesting that Ms. Roth is here in that capacity. My observation is that many of the leaders in independent living centers are in fact disabled in a way which would formally qualify them as developmentally disabled, even though they may not choose to participate in that.

Developmental disability is not the province of a particular State agency in spite of the way it is sometimes represented. That has raised some issues in terms of the roles of the administering agencies, which I think will be addressed in some other testimony.

One of the things that I hope will happen is that the State agencies, the various State agencies—rehab, education, health and so forth—that are represented on the State Councils, that those representatives will become more active and will use the State Councils as a forum for discussing their relative roles and how they can compliment one another.

Our own Council has from time to time been the convening body—whenever you get two or more State agencies that have conflicting interests, you really have a problem in getting some neutral territory for them to discuss their differences in; you can't always take them into the Governor's office. The Councils can perform a role in that area.

We talk about planning. Back in 1965, the State planning activities were conducted under Public Law 88-156, one of the two Kennedy bills—which incidentally was an idea that was incorporated in the DD Act when we did it. The activities that went on there were called "planning", and somebody who was a professional planner said afterwards that the government got many times its $2 million worth of activity, but very little of it was planning. Well, we don't even pretend that the 1990 reports are plans; they were assessments, they were documentation of facts and scopes and difficulties and all the rest of it.

There is a need for more concerted, sophisticated, long range planning, and that cannot be done by the Councils alone. The State agencies themselves that have programmatic responsibilities have to do their own, and they have to be somehow synthesized. It has to be a synergistic process. And I am hoping that will come about.

Finally, there will continue to be certain unresolvable dilemmas. There are some things that are troubling in our field that are basically ethical issues, ethical dilemmas that have been with us for two or three millennia. The conflict between paternalism and autonomy, for example. To what extent do we as a society have an obligation, a need, a duty, to protect people who are vulnerable, versus how much should we allow them to make their own mistakes, and to what extent can we allow them to imperil themselves.

This is a dilemma which will not go away by any act of Congress or any particular act. We have to continue to struggle with this.

Similarly we will continue to struggle with the relationship between generic services being mainstreamed, being part of a general system, and the need for some specialized and particularly expert attention to those characteristics of people which are controlled by the fact that they have an impairment which is not common to all people.

I think those issues will continue to confront us in the next decade and indeed in the next century.

Senator HARKIN. A very good dissertation. I'd say that's pretty comprehensive.

Dr. Lakin, on the design project for the survey, couldn't that be done under the Projects of National Significance Program?

Dr. LAKIN. Well, I suppose it could be. The level of funding required would be substantially more than that would now permit.

I would really argue very strongly against diluting that program as presently written. It is very little funding for research, and some of the things that are done are just—they are the attempts to go out and find what is innovative in our country, to develop and demonstrate new ways of doing things. They have been potent projects, and I would certainly hate to see the funding available for that kind of work diluted by a national study, which really has relevance to a wide range of agencies.

So I'd say yes, but please don't tamper with what has been established there. Things like supported employment have been driven in very large measure by grants that have come out of that program, and of course, some of the ongoing data collection system, the work that we have done with others around the country.

That might be an evasive response, but that is sort of how I feel about it.

Senator HARKIN. Senator Durenberger?

Senator DURENBERGER. Dr. Lakin, let me say I agree with your response, and I do not think you are evasive at all. I think the notion here is that in that particular part of the Secretary's office, he is supposed to be thinking about better ways to do thing across-the-board. And I hate the word "efficiency" in connection with these sorts of things, but this is a way to improve the quality of service delivery to implement these policies. And that is what the Secretary should be interested in in a variety of these areas, and he ought to try to find the money in the P&P budget or through an appropriation or something like that.

Dr. LAKIN. I would just say that at times the Senate has spoken to the need for studies that are sort of multiple-agency activities through the DD Act. But I surely would hate to see funds taken from the Act to fund those things.

Senator DURENBERGER. Some have suggested the need for an increase in the UAP core funding. What do you think the value of the core funding is, and do you believe an increase is needed? And if more funding is needed, what additional steps should we undertake in the area of accountability?

Dr. LAKIN. Well, personally, and just from a perspective of fairness, I would say the first priority ought to be to make sure that all States have at least one UAP. I don't think I could justify our getting more money until other States have something.

Second, the value of funding is really that it has allowed us to go out and develop new programs in areas that we needed to be involved before we had a capacity that would allow us to be competitive in other kinds of grant programs. So we were able to use our core funding to bring people in, begin programs, and then to sustain those programs through State funding.

So it is tremendously, tremendously important to building a comprehensive program, and a larger core grant would allow us to do new things, things that we could easily identify. It is important money because it is leveraging money.

Senator DURENBERGER. On the issue of accountability, we are not at the stage yet where there is enough money available so that we have to worry about the fact we are spreading too much around and not getting anything for it—I assume. That's my impression listening to the testimony this morning, that we are a few years away. I mean, we can keep track of you folks pretty easily, just with hearings.

Dr. LAKIN. Well, I guess I feel that some degree of competition is extremely important to quality assurance in anything. I think the reason why we are falling short in many places in our residential services is that people don't have choices; there are waiting lists for every spot that opens up. If there were more capacity than need, the quality that people had to deliver in order to stay in business would increase. I think to some extent that is true of anything. If we were open to competition from other universities within the State, I don't think we would suffer a bit, and I know people with developmental disabilities wouldn't suffer, but I'd sure hate to suggest that in a roomful of my colleagues.

Senator DURENBERGER. Let me ask you one other question which relates to two of the recommendations you made in your statement—and Ms. Roth may want to comment on this, too, and Dr. Boggs as well.

Two of the interesting points that you made that we should be considering, one was the issue of the technology of positive behavior management—an area that is obviously developing across the field—but as it relates here to behaviors in community settings in particular and some of those kinds of problems, maybe you could elaborate on just exactly how we can help in that area.

The second one is related to that, and that is the technology-technology. You gave the example of Roger and the baseball pitching machine. But the whole area of computer-assisted communication and all of the rest of this incredible technology we have available to us ought to be a positive in the integration movement. Maybe you have some specific suggestions about what we can do to facilitate progress in that area.

Dr. LAKIN. Well, I am a believer that often we in the field can teach each other a lot. I think these are two areas in which we would benefit from a limited number of support projects that could come in and help our training projects, both the ones that are directly written into the law and the other training that we do, to develop the capacity so that when we go in the field we are able to teach people to better use positive behavior management practices.

It is a frustrating business out there, and I can tell you from experience at times the desire to use punishment is incredibly strong, because punishment works; the problem is it doesn't teach anything, and it degrades people, and it ruins relationships, and it is dehumanizing, and it really has no business in our interactions with people to the extent that we can limit it, but we need to know how to do it, and that technology is there. There are excellent people around the country who could teach us how to use it, and I'd like to see them integrated into the training program.

The area of technology is much the same, tremendous capacity building deriving from the technologies available today. And I don't speak best about those, but I think we could learn a tremendous amount by integrating experts in those areas into our network of University Affiliated Programs, and I would urge you to look to ways to help us do that.

Senator DURENBERGER. Thank you.

Thank you, Mr. Chairman.

Senator HARKIN. Ms. Roth, I just wanted to bring up one thing, and again it is sort of getting back to what Dr. Boggs had talked about. It has to do somewhat with coordination and the technology-related assistance bill that we passed in 1988.

I was wondering if you could speak to the importance of coordination between the programs that we have created by the Developmental Disabilities Act and the Statewide coordinating bodies that are being coordinated in the States that are applying for grants in the technology area. Are they being coordinated?

Ms. ROTH. Let me say that I do come from a State that has one of the assistive technology grants, and in my opinion one of the most important things of the grant so far has been that it has brought agencies together. And I think that it is helping them to coordinate better than any other mechanism that I have been aware of previously. I think that process is almost as important as the types of systems changes—well, that is a systems change, the fact that that type of coordination is coming as a result of it.

I cannot speak about other States; I just note that in Utah, it is making a big difference in terms of coordination.

I want to say that I agree with Ms. Boggs that independent living at this point it seems to me is quite closely related to developmental disabilities in terms of the way it is conceived in the Act.

And I want to tell both you, Senator Harkin and Senator Durenberger, that I read the DD Act for the first, time, I have read the Rehab Act, I have read the independent living parts. The DD Act to me, with its Bill of Rights, is written in a way that—gosh—I just want to congratulate you on it because the language is excellent, better than any disability-related act I have read; the concepts of control over one's life and of looking at outcomes and not just services, are excellent.

I feel really good about the Act as it does stand, although I know there are a lot of things that it needs to do.

Just one more thing I wanted to say is that I recognized when I addressed assistive technology that it is a very specific thing and that there may not be money to put into assistive technology. The Technology Assistance Act works on changing systems to do better assessment, to follow up on technology, that type of thing. But there isn't appropriations to actually buy the technology——

Senator HARKIN. That's the next step.

Ms. ROTH. Yes, I hope so.

Senator HARKIN. We wanted to get the technology assistance bill through, get the coordination and set up the systems, as you said, to get the systems set up. It is hard to get the hardware and so on if you don't have the systems set up.

Ms. ROTH. Absolutely.

Senator HARKIN. So we are hoping that in the States that have applied for grants, they get the systems set up, and we hope that the next step is, then, the technology itself.

Ms. ROTH. Yes. You know, the thing that made me think of the possibility of creating a foundation is I just started to look back on the March of Dimes, which did generate money to buy various services and assistance that people with polio needed. And I started to wonder if that would be possible these days. And to tell you the truth, just with my grassroots kind of work and the types of donations that we are able to generate just on a very small level, I honestly think that seed money to go to States to try to develop statewide foundations possibly could be successful.

Senator HARKIN. Bobbie was just telling me that was one of the purposes of the Act was to get going in that direction.

Ms. ROTH. Yes.

Senator HARKIN. Unless there is anything else, we thank this panel for being here again and for all of the wonderful work you are doing in all of these areas.

Ms. ROTH. Thank you very much.

Dr. BOGGS. Thank you.

Dr. LAKIN. Thank you.

Senator HARKIN. Our third panel is Ken Campbell, Director of the Ohio DD Planning Council, testifying in behalf of the National Association of Developmental Disabilities Planning Councils; Henry Brown, from Greenville, SC, testifying in behalf of the National Association of Protection and Advocacy Systems; Dr. Al Healy, Director of the Division of Developmental Disabilities, the University Affiliated Facility at the University of Iowa, and he will be testifying on behalf of the American Association of University Affiliated Programs. He is accompanied by Kim Hurley, who is from Volga, IA—that's up in Clayton County—and I'll have more to say about Kim in just a second here.

I wanted to say also that Senator Metzenbaum has been a longtime supporter of people with disabilities, and he wanted to be here to hear Ken Campbell, but he wasn't able to come because of a scheduling conflict. He just wanted you to know that, and he wanted to congratulate and compliment Mr. Campbell for his leadership on behalf of people with developmental disabilities.

So again, welcome to you all. We'll start with Ken Campbell, who has been Executive Director of the Ohio DD Planning Council for about 3 years. He is a member of the Council as a consumer representative for the Spina Bifida Association. He is also a candidate to become president of the National Association of Developmental Disabilities Planning Councils and is currently chair of the Adult Issues Subcommittee of that organization.

Welcome to the subcommittee, Mr. Campbell.

STATEMENTS OF KEN CAMPBELL, EXECUTIVE DIRECTOR, OHIO DEVELOPMENTAL DISABILITIES PLANNING COUNCIL, ON BEHALF OF THE NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITIES PLANNING COUNCIL; HENRY BROWN, GREENVILLE, SC, ON BEHALF OF THE NATIONAL ASSOCIATION OF PROTECTION AND ADVOCACY SYSTEMS; DR. ALFRED HEALY, DIRECTOR, IOWA UNIVERSITY AFFILIATED PROGRAM, IOWA CITY, IA, ON BEHALF OF THE AMERICAN ASSOCIATION OF UNIVERSITY AFFILIATED PROGRAMS; AND KIM HURLEY, UNIVERSITY OF NORTHERN IOWA, ON BEHALF OF UNIVERSITY AFFILIATED PROGRAMS

Mr. Campbell. Thank you, Mr. Chairman.

I am here, as was mentioned, on behalf of the National Association of Developmental Disabilities Councils, and I'd like to start with a brief history of the 20 years that Councils have been in existence and the difference that we have seen in the focus of Councils from facility-based to family and individual support in the community. We see that particularly in the 1987 Act Amendments, where Congress mandated the educational policymakers through the service analysis and the national consumer survey that we have heard referred to as the 1990 reports.

Councils are structured in a unique way in that they are made up of State agency representatives, representatives of higher education, providers of service, and a 50-percent consumer representation. This makes them quite a unique body—a body that, when issues are brought to that body and worked through, they have been through many of the areas where we have concerns with turf and varying issues amongst that very broad scope of individuals.

However, major issues have been addressed by Councils over the years, and great successes have been seen. I would like to point out three areas where Councils have seen major successes, one of them being the area of supported employment.

Dr. Paul Wehman of Virginia Commonwealth University is a recognized national expert in the area of supported employment and reports that funding increased 300 percent between 1986 and 1988 for supported employment, and during that period of time Councils contributed over $9 million. A near $9 million contribution from a small program like Councils was highlighted in a particular way, looking at the Indiana Council's experienced, where they were the catalyst and coordinator for four State agencies' involvement in establishing a viable program in Indiana, which grew from 9 to 36 providers between 1986 and 1989.

However, even with this kind of effort being generated by Councils, a great deal of work remains to be done. The National Consumer Survey that was mentioned brings out the point that 22 percent of people with developmental disabilities over the age of 16 are working full-time; 24 percent are working part-time. Of those working—which is less than half the total—23 percent are in sheltered employment; 19.43 percent are in competitive employment, and 4 percent in supported employment. Nine percent of those in competitive employment have limitations in all seven major life areas that are listed in the developmental disabilities definition. This is of major importance because it shows that competitive employment can work for anyone.

What this means to people with developmental disabilities, which is probably the most important issue that I would like to deal with, is I think summed up in a quote from an individual, a gentleman from Illinois with a developmental disability. It goes like this: "I want you to know that integration is just getting started. It is like the Berlin Wall, where a big wall divided the city for years and years. On TV, I saw people rush through the gates in the Wall when they opened up. No one got shot by the guards like the used to, but the Wall was still there. My mom says it's not just the Wall that separates them now. It is their ideas, the way they live and think. For us who have disabilities, it is just about the same: The gates are still open, but the wall is still there."

The second item I'd like to look at in terms of the Councils' accomplishment is consumer empowerment. We want to look at ways in which people with developmental disabilities can be in control of their own lives.

The Minnesota effort, which has a priority on accountability to individuals and families, and their effort in the area called Partners in Policymaking has been mentioned in earlier testimony. It is currently being replicated in Alabama, and Ohio has an empowerment strategy being put into their plan at this time. Again, work remains in this area. We have just barely, I think, scratched the surface and begun to realize the direction in which we might want to go.

I think that the third area to look at relates to individual and family supports. The area of individual and family supports has been enhanced recently through a Grant of National Significance to the Human Services Research Institute and United Cerebral Palsy of America. This has made a difference in Ohio. Ohio has had a family resources line item in their budget for a number of years. We have recently seen the direction taken and the services provided and improved upon dramatically through this Grant of National Significance and the information provided through this grant, which pulled families together and empowered individuals to improve Ohio's program.

The Director of the Ohio Department of Mental Retardation and Developmental Disabilities says he looks forward to the day when the family resources budget is bugger than the institutional care budget in the State. This shows that we continue to have work to do in bringing people the kinds of supports they need in the community.

The Illinois experience in regard to this relates to the interviewing of 721 families to determine what their needs were, which led to pilots funded in 1988 and 1989 and 1990 by their Council, and now they have a fully-funded program in the area of individual and family supports that is State-funded.

I think in looking at the future, it will be keyed from the 1990 reports. The consumer surveys that were done report that the system is the major target for change. Better access and choice must become a priority for us in this day and age.

A mandate showing your support for a priority which strives to make the system supportive rather than stressful is needed.

I'd like to quote from a parent in Utah who says: "I can either deal with the system, or I can deal with my kids. I can't handle them both." That just shouldn't be. We have no current focus on systems issues in our current listing of priorities. Issues of service coordination and consumer participation are primary elements of this issue. The system is an entity that consumers have as a part of their daily lives. However, it is not always a positive or friendly one.

We need to consider looking more seriously at things like informal supports, friendships, community associations as key elements of our needed priority. Iowa has done this in taking an aggressive public education plan and applying it to all of its Council's projects.

Quickly, to look at administrative issues within the Act, we find that Councils in order to do their job of advocating must be independent. They must have authority over their expenditures. The 1987 Amendments required gubernatorial review of the designated State agency. We need to try to maintain that option, keeping that option open, to assure that Councils will continue to be allowed independent functioning.

We also would like Congress to encourage Governors to fill openings in Councils promptly to assure that proper representation is maintained, that 50 percent representation of consumers specifically. Clarification of matching rates in relation to poverty areas would be helpful, and of course, it has been mentioned and needs to be stressed I think and mentioned again that funding for such a small entity that has been so successful is extremely important.

Since 1973 in real economic terms, this program has lost 20 percent funding. In 1972, the Basic State Grant Program was authorized at $60 million. It took 19 years to reach that level. We need to see some rectification of that situation in 1991.

I think the 1990 reports and where they go from here really will be seen after they are kicked off by the press conference that Senator Harkin will be sponsoring on May 23rd. I think we need to look at those from the perspective of State and Federal combined approach implementing the recommendations of those reports over the next ten years to take us in the proper direction.

It would be beneficial if our law would reflect the use of the reports in the activities of the Council. I think the 1990 reports have been the best example of University Affiliated Programs and Protection and Advocacy Agencies and DD Councils working together that we have seen. The technical assistance that was made available through a Grant of National Significance that allowed the 1990 reports to be so successful, with specifically the help of Temple University's DD Center and the Institute for the Study of DD at the University of Illinois, which helped dramatically in the formatting and planning of those activities, was a major portion of the collaboration, followed by many States contracting with their UAP's to do consumer surveys, and the work of P&As often went in the direction of organizing public forums and case studies for those 1990 reports. It was a collaborative effort that has not been matched. We applaud it and hope to continue it.

In order to do that effectively, we feel that UAP networks must be expanded to all States so that that resource is made available.

In the area of Grants of National Significance, again, the 1990 reports show us that those grants provided critical information. Examples are the expenditure information from the University of Illinois-Chicago, residential services information from the University of Minnesota, and employment information drawn from Children's Hospital at Boston, Massachusetts grants. Those grants provide invaluable information that we need to see continued.

In regard to the consumer survey data, we haven't analyzed it. We don't know nationally exactly where we are going, as has been mentioned, but it is key that this is the beginning of a database that must remain updated and that we must build on in order to take us into the Nineties in the right direction.

I thank you for your time.

Senator HARKIN. Thank you very much, Ken, for a great statement.

[The prepared statement of Mr. Campbell follows:]

PREPARED STATEMENT OF THE NATIONAL ASSOCIATION OF DEVELOPMENTAL DISABILITIES COUNCILS
KEN CAMPBELL, ON BEHALF OF

Good morning. My name is Ken Campbell. I am the Executive Director of the Ohio Developmental Disabilities Planning Council and I am testifying on behalf of the National Association of Developmental Disabilities Councils (NADDC). The Association appreciates the opportunity to testify on the reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act.

This October will mark the twentieth anniversary of the passage of the Developmental Disabilities Assistance and Bill of Rights Act. That legislation authorized the establishment of Developmental Disabilities Councils in every state and territory, Councils that today are active, visible and viable partners in the systems which provide supports and services to people with developmental disabilities.

These systems are defined much more broadly in this twentieth year of the Councils' authorization: even the title of the first version of the Act reflects what today is a limited and outmoded view of people with developmental disabilities and the system which served them: it was titled the "Developmental Disabilities Services and Facilities Construction Act." People with developmental disabilities were thought to need "places" and Councils were to help decide how to construct those places; services in the community were recognized but with less emphasis. However, even then and within those parameters, many innovative approaches were begun by Councils and the dimensions of people with developmental disabilities began to be recognized.

As our ideas and the system changed, so did the Developmental Disabilities Act, both in terms of its goals for the system and the expected actions of the Councils, reflecting the practice of some of the most forward-thinking, activist Councils and providing encouragement and impetus for other Councils to move forward.

In the 1970's, the role of the Councils as advocates for policy change was established, defining the purpose of that advocacy as supporting community based services and reducing the use of institutions. No longer did Councils use Basic State Grant funds to encourage building buildings.

The 1987 Amendments reflected further changes in the service system's approach, stressing the importance of the family and the community in providing services and supports to meet people's needs and to recognize the potential of people with developmental disabilities as contributing members of society.

In the 1987 Amendments, Congress reasserted its belief that

Councils were key players in moving public policy forward. Congress mandated this by including the education of policy makers as a major Council activity, by stressing the need for an autonomous Council advocating change within state government, and by asking Councils to prepare an important and pivotal report: now called the 1990 Reports.

Congress asked Developmental Disabilities Councils to look at policies and practices within their states and territories and to report to Governors, legislatures, the Congress and the general public about the results. Congress also said that the reports must include information obtained directly from people with developmental disabilities and their families through a survey: the National Consumer Survey. The mandate of these reports solidified the Councils role as educators of policy makers and also supported their roles as change agents and connectors to people with developmental disabilities. The reports were not to be left on shelves to gather dust; the Councils are to use the reports as the basis for their future work to improve the lives of people with developmental disabilities.

WHAT COUNCILS DO

The Councils have a unique design and a unique mandate. Half of the members of Councils must be consumers: people with developmental disabilities and their family members. These consumers are joined by representatives of state agencies, of services providers, and of other organizations to work together in partnership to consider issues affecting people with developmental disabilities. The Councils also have authority over the Basic State Grant funds which can be used to study issues, to plan for change, and to implement new ideas.

The 1990 Reports in many ways were not different from the activities that Councils have always done: examining the state system, listening to consumers, developing plans for new and better ways to meet people's needs, and using the Basic State Grant funds to nurture and support those ideas into reality.

The Councils' ongoing activities during the last three years, in addition to developing the reports, evidence their success and also show how Councils will respond to the issues raised in the 1990 Reports. A few key areas bear examination:

SUPPORTED EMPLOYMENT

Since 1984, Councils have been required to include employment as one of their federal priority areas, the areas in which Councils choose to focus their attention and use Basic State Grant funds. Paul Wehman of the Virginia Commonwealth University, one of the nation's foremost researchers on supported employment, points to this mandate as the beginning of federal and state response to the need for a new way of meeting the employment needs of people with developmental disabilities. The concept of supported employment was relatively new in 1984; its premise was that people with developmental disabilities could work in competitive jobs, in regular places of work, with other workers in the general community, if they were provided the right instruction and ongoing supports. Developmental Disabilities Councils have worked to change state systems to build supported employment opportunities. In the words of Dr. Wehman:

> Collectively these agencies (Developmental Disabilities Councils) have contributed in excess of $9 million over the three-year period (FYs 1986-88). Typically, these funds were used for a variety of support or supplemental activities that facilitated a supported employment initiative while not necessarily funding direct services delivery.

One Council's experience demonstrates this. The Indiana Council was able to coordinate with four state agencies to assure that state and federal funds were made available last year for supported employment and that they be used to encourage use of supported employment opportunities not as an adjunct to the employment and training system but as a viable option for all people with developmental disabilities. To set the stage for this change in the system, in conjunction with the employment mandate in 1984, the

Council used a minimal amount of Basic State Grant funds to leverage establishment of training programs, including participation and additional funding by local Job Training and Partnership Act programs. Partly as a result of these efforts, 36 rehabilitation providers across the state are now providing supported employment, where in 1986 there were merely 9 such providers.

Councils in Washington, Arizona, Ohio, Montana, North Carolina, Georgia, Massachusetts and others report that similar activities have been successful in increasing the use of the supported employment option in their states. The types of activities referenced by Dr. Wehman are supported by the planning and coordination activities that Councils, by virtue of their varied membership and position in state government, can use to exercise additional influence. Dr. Wehman reports that funding for supported employment from all sources increased over 300% between FY1986 and FY1988; Council activism as well as funding can surely be cited as major factors in this increase.

Yet despite these achievements, much more work must be done. The National Consumer Survey reported that only 22% of adults age 16 and older were working full time and another 24% were working part time. Of those 23% were still in sheltered employment, 19.43% were in competitive employment, and only 4% were in supported employment. The positive aspect of this data is that 9% of the people competitively employed had significant limitations in all seven of the major life areas in the definition of developmental disabilities, documenting that the severity of disability should not be thought to preclude competitive employment.

INDIVIDUAL AND FAMILY SUPPORTS

Providing supports so that people can live independently and to enable families to keep children who have disabilities at home has been a primary area of activity for Councils. As the use of institutional settings has become less and less acceptable to parents and individuals, Councils encourage the establishment of supports that bolster families and individuals, not overwhelm them.

Forty-two states now have some form of family support program; Councils, including those in Wisconsin, Michigan, Ohio, New Jersey and Colorado, have been instrumental in their establishment in virtually all those states. Other Councils are now working to establish state family support programs. In Illinois, two years of study, including the interviewing of 721 families, led to funding of family support pilots in 1988, 1989 and 1990, serving hundreds of families, including those of persons with severe mental illness. The evidence of the pilots and the related public awareness effected by Council and state legislative leadership led to funding of family support by the Illinois legislature this year. The Council will play an ongoing role in providing technical assistance and evaluation to assure the program continues to meet the needs of families.

In 1985 the Oregon Council established a Family Support Initiative; in 1987 they agreed to co-fund demonstration projects with the state mental health agency. The Council is working now to educate policy makers, using the information gained by the demonstration projects to establish a permanent state-financed program. Massachusetts emphasizes assuring that families know about new ideas such as family support so that they can effectively make their preferences about services known to policy makers. Minority families are a particular focus.

In Virginia, personal care services--which provide daily living supports to people who need assistance for personal needs such as dressing and transferring and are the key to independent living for many people with disabilities--was defined as a critical need through both the Council's planning activities and in the consumer survey done for the 1990 Report. The Council established a consumer-directed project to study, develop and demonstrate that personal assistance services can enable independence and enhance potential for productive employment.

While many of these initiatives require that Councils demonstrate a new type of support or element of the system, the requirement in the 1987 Amendments that direct services can be done for a limited time only and must be accompanied by a plan for inclusion in the regular system has been of great help in enabling Councils to get support for their initiatives and in emphasizing activities such as training, educating policy makers and outreach to unserved individuals and families.

While progress has been made in increasing awareness of the importance and viability of individual and family supports, many state programs are limited in scope, with many still in the pilot stage. Thus, it is not surprising that in the 1990 Reports increased availability of family and individual supports remains a critical and universally identified need. In the National Consumer Survey, respite care, a typical family support service, was cited as a high or urgent need by 67% of those who need it at all; of those who say they need it, only 24% are currently receiving respite care for caregivers. When dissatisfaction was expressed by respondents it was simply because they could not get enough to meet their needs.

CONSUMER EMPOWERMENT

A frequent choice of states in defining a state optional priority area is consumer empowerment. This reflects the belief in the disability movement, reflected in Councils' actions, that people with disabilities must know their rights and options so that they may exercise full choice in directing their lives and in seeking supports to make their lives as productive and integrated as possible.

In Minnesota this is expressed as a priority on "Accountability to Individuals and Families." In California, program development funds were targeted to assist with the establishment of self-advocacy and support groups. In Los Angeles alone, the Los Angeles County Self-Advocacy Advisory Group established 14 local groups designed to help people with developmental disabilities to speak for themselves, enhancing their independence, productivity and making it possible for them to become fully participating citizens.

The Maryland Council has supported the Maryland Coalition for Integrated Education (MCIE) to organize local parent groups to advocate for integration in local school programs as well as for state level policy change. Alabama replicated a model developed by the Minnesota Council, the "Partners in Policymaking" program, which trains people with disabilities and parents about public policy, presents expert information about the latest developments in services and supports, and encourages them in advocacy activities for themselves and others. This intensive training creates community leaders who can then share their skills with other consumers and parents.

In the National Consumer Survey, 22% of the primary consumer respondents said they were members of advocacy groups; 30% of the respondents indicated that a family member was a member of an advocacy group.

THE FUTURE

While the existing priority areas, including the state optional priority, have allowed Councils considerable opportunity to create changes in identified problem areas, new "cutting edge" problems and solutions are always on the horizon. The 1990 Reports have made many recommendations that address the existing priority areas: employment, community living, child development and case management. None of these priorities is obsolete; work to gain jobs for all those who want them, to enable living in homes with supports, to ensure all children get the services they need to grow up healthy and able to use their full potential--all these are still goals.

But the overwhelming evidence in the 1990 Reports indicates that more must be done with the whole system than in any one of its parts. The Reports clearly identify the need to change our beliefs about the needs and potential of people with developmental disabilities and the organization of the system that we have designed to attempt to meet some of these needs. These are much more pervasive and difficult issues and there is currently no federally empowered focus for addressing these problems.

NADDC, with the support of the Consortium of Citizens with Disabilities (CCD), is suggesting the expansion of the case management priority area in order to emphasize these issues. This priority area is needed not merely to allow Councils to conduct focused activities but to do what the Developmental Disabilities Act has done for twenty years: express Congressional interest and leadership for innovations and new waves of understanding. Our recommendation builds upon case management, a current priority, but reaches further to address the coordination of services, the full access to services and supports, and the enhancement of informed choice on the part of consumers.

Consumer participation is a key element of this suggestion. The Congressional mandate to conduct the consumer survey gave an important emphasis on the use of consumer-based information as the foundation for planning and developing the system. Through the voluntary cooperation of the overwhelming majority of Councils in using a uniform survey instrument, there now exists a data base of over 14,000 individual voices, speaking about their lives and their needs. Expression of that consumer voice in directing the system should be supported. An expanded priority area, focusing on access and choice, would emphasize Congressional belief that the consumer should be heard.

Access and choice are tied to other aspects of the total system. Linkages between programs are a critical element. In Nebraska, the

Council funded pilot programs with school districts across the state to develop ways to help students move from high school into the adult world of work and independence. Cooperation was elicited from the schools and support and training was provided to teachers to enable them to better assist their students. State regulations requiring transition were also established. Coordination and support and training to enable those working in the system to adapt to change are essential parts of this expanded priority.

Because of the organization of the system, people often fall between the cracks of agencies or programs despite the pressing nature of their needs. This was one reason the 1990 Reports were needed. Councils have found that many people are underserved--services are not fully available or they are "underserved" because the services do not effect independence, productivity or integration. Those outside the system include persons in minority groups whose cultural differences mitigate against access to the system. Agency practices or definitions also cause consumers to be excluded.

The "system" is an entity to consumers, a part of their lives. And it is not always a positive or friendly part. As a parent from Utah stated during the 1990 Report process: "You know, I can either deal with the system or I can deal with my kid...I can't handle both." The Councils have a responsibility, which will be buttressed by Congressional support for an expanded fourth priority area, to consider the breadth of the system and its impact on people with developmental disabilities.

The community at large is also a crucial part of the equation for full integration. Connecticut has been a leading Council proponent of the importance of reaching out to the community to enhance the potential for positive futures for people with disabilities by building connections with people and associations in the community. In working directly with individuals and families, the Council found many overtaken and overwhelmed by service providers and professionals which tended to emphasize labels and deficiencies and which isolated people from natural community supports. The Council played a direct role in financing technical assistance provided directly to individuals and families, training, creating public education materials, creating an agency and leveraging on-going support funds, analyzing services and supports, and supporting conferences.

Iowa too has recognized the importance of involving the general public. Every Iowa Council project now includes a public education component. The Council developed its own public education plan, emphasizing what people could do to affect the lives of people with developmental disabilities.

Vermont has worked to change the building codes to assure increased physical accessibility in communities across the state.

Washington state is not only working on the availability of family support services but is also emphasizing the community, developing and demonstrating a model family support network of neighbors and community members within a local area.

These Councils and activities demonstrate that there are new ideas coming from Councils and that issues often bridge several specific areas. The recommended priority would emphasize that the issues of consumer access, involvement and choice, design of the system and local community involvement are pivotal in achieving full independence, productivity and integration into the community for people with disabilities. It would focus attention on the wide range of issues and variety of systems which affect the lives of people with disabilities. It could embrace the wealth of new approaches to enabling people with developmental disabilities to achieve full citizenship.

OTHER ADMINISTRATIVE ISSUES

In order to fulfill the mandate of advocacy given to them, Councils must be able to act independently and with the respect and stature that comes from their establishment by the Governors of the states and territories.

NADDC has identified several areas which need clarification to ensure Councils' conflict-free and effective advocacy. CCD has developed recommendations in these areas which NADDC strongly endorses. They include the following:

Councils must have authority over expenditures to assure that state plan objectives are implemented as the Council envisioned. By clarifying that this is a Council responsibility and that the role of the designated agency is to receive and disburse funds at the direction of the Council on behalf of the state untoward control by the agency will be avoided.

The 1987 amendments directed a review of designated agencies. This has, by and large, been a positive experience. Of the 29 Councils placed in agencies providing direct services, 4 remained, with some using this requirement to negotiate better arrangements. Four Councils moved to a non-service providing agency and five Councils are still discussing a move from a service provider. There are still a few Councils which wanted to change, were supported by public comment to change but for a variety of reasons were not changed. Therefore, NADDC, supported by CCD, would like Councils to continue to have the option to recommend further gubernatorial review of placement.

For Councils to function optimally , their membership must be up to full strength. Congress needs to urge governors to fill vacancies of citizen Council members in a timely way so that the mandated composition of one-half consumer members is in place at all times. Also, Congress needs to clarify again that the Council director is supervised by the Council and that other staff are supervised by the Council director. This should solve many of the problems encountered by some Councils in these two key areas.

We have also made two recommendations regarding matching rates: to clarify when poverty area activities can be matched at a lower rate and that the designated agency (administrative) match should be included in the determination of the 25% required aggregate. Clarification is needed as we feel that it was Congressional intent that all state and local contributions to the program support the goals of independence, productivity and integration into the community and thus should be included in the aggregate match.

Finally a critical support to the program is funding.

The Developmental Disabilities Basic State Grant Program is probably one of the only human services programs to take pride in its smallness. Councils have demonstrated that through credible policy analysis, public education and the seeding of larger initiatives, many more services and supports have been created for people with developmental disabilities on the state level than could ever have been expected from financing under the Developmental Disabilities Act alone. While our smallness has had a large impact, the program has been losing ground steadily since

FY1973. In fact since that time, in real economic terms, funding actually was reduced by more than 20%--a very bleak economic picture. Therefore, Developmental Disabilities Councils, supported by CCD, are recommending an increase in the minimum allotment for 13 states and territories and appropriations for the Basic State Grant Program at $81.27 million for fiscal year 1991. In 1972, the Basic State Grant Program was authorized at $60 million. It took until the current fiscal year--19 years--to reach it. Fiscal year 1991 must be the year when this significant disparity is rectified.

THE 1990 REPORTS

Many new ideas are found in the Councils' 1990 Reports. NADDC has just completed a compilation of the reports, cataloguing key issues, barriers and solutions. This is being used by the Administration on Developmental Disabilities to develop the Secretary's Report to Congress and by NADDC to identify key national advocacy issues. NADDC will present these findings at a press conference, sponsored by Senator Harkin, on May 23, 1990. NADDC is also working with the National Governor's Association and the National Conference of State Legislatures to support use of the reports at the state level. Councils are hopeful that this will spark continued movement forward on the critical policy issues that affect people with developmental disabilities. Councils are eager for the information in the reports and in the National Consumer Survey to be used by Congress and other policy makers to influence the next decade's activities both at the state and federal levels. We hope that Congress will create an opportunity for full presentation and use of 1990 Report findings.

As indicated in the CCD testimony, we feel the law should reflect the use of these Reports in the Councils' ongoing activities over the next period of reauthorization.

Another issue which comes out of the 1990 Report process is the CCD recommendation to expand the list of federally-assisted programs to be reviewed as part of the Councils' analysis of the system, adding child welfare, transportation and technology; the CCD also recommends that these federally assisted programs be reviewed even if specific state plans are not required. In current law, only plans are to be reviewed thus potentially limiting the Councils' inquiries. The 1990 Report process showed that many generic programs and policies (such as transportation and housing) affect people with developmental disabilities and that these programs should be considered in the Councils' ongoing review of the entire system.

The 1990 Reports were also instrumental in bringing Councils and their sister programs in the University Affiliated Programs and Protection and Advocacy systems to heightened working relationships. Many Councils contracted with UAPs to conduct their consumer survey, to prepare the policy analysis or to hold public forums. Protection and Advocacy systems in many states participated in or organized public forums, some prepared analyses of their case and information/referral records to identify problems and issues, and some provided case studies (protecting confidentiality) to illustrate with real people the impact of system problems. Virtually all UAPs and P&As participated in the review process prior to publication of the 1990 Reports.

The American Association of University Affiliated Programs and the National Association of Protection and Advocacy Systems are members of the Advisory Group to NADDC's 1990 Report technical assistance project, funded under the Projects of National Significance. Their participation, along with many other consumer organizations and Council representatives, has provided invaluable advice. Two University Affiliated Programs have provided considerable assistance in this effort. Temple University Developmental Disabilities Center in Philadelphia has developed the instrument, provided many hours of technical support to Councils and has done the preliminary analysis of the National Consumer Survey. The Institute for the Study of Developmental Disabilities at the University of Illinois-Chicago provided support and technical assistance on the policy analysis technical assistance throughout the past two years. NADDC and Councils are grateful for their support and for the availability of this type of resource in the entire University Affiliated Program system.

NADDC endorses the CCD recommendations to build in on-going coordination and collaboration between and among Councils, UAPs and P&As and particularly supports continued expansion of the UAP network so that the remaining 9 states and Puerto Rico can benefit from UAP expertise.

PROJECTS OF NATIONAL SIGNIFICANCE

The Projects of National Significance, as just referenced, have supported the technical assistance on the 1990 Reports as part of the continuing funding of technical assistance projects to the three program components.

NADDC supports the CCD recommendation which urges multi-year funding of technical assistance to assure that the programs receive useful assistance and direction, to enable them to fulfill the mandates Congress has given them.

NADDC also supports the CCD recommendations relating to data collection. The existing data projects funded with past PNS funds (and other sources of support) were invaluable resources for Councils in developing the 1990 Reports. The expenditures data base at the University of Illinois-Chicago, the data on residential services at the University of Minnesota, and the data on employment collected by the Children's Hospital in Boston, Massachusetts are all critical to our continuing understanding and documentation of the changes occurring in the patterns of services for people with developmental disabilities. Congress has called upon these resources many times to illuminate critical legislative issues. States have used this information to measure their achievements against other states and to pursue needed changes.

NADDC supports continuation of these efforts and also supports a method to discuss and plan for future information and data needs, as described in CCD's recommendations. Also NADDC strongly supports inclusion of continued analysis of the National Consumer Survey Data by Temple University and others to elicit the full value of that information and bring it into the public dialogue on policy. Given the limited amount of time between states' completion of the survey and the preparation of reports this spring, only minimal analysis can be done. NADDC urges that the consumer survey data continue to be analyzed with support from the Projects of National Significance.

In closing, I would like to thank the Subcommittee for a chance to tell you of our activities over the past three years, including the development of the 1990 Reports. The confidence you have expressed in Councils ability to move public policy forward to support the independence, productivity, and integration into the community for all people with developmental disabilities has been taken as a challenge to further excellence by all of us in the developmental disabilities movement. Our recommendations reflect our best thinking about where we need your support and where we must go next to strengthen our joint commitment to people with developmental disabilities.

Senator **Harkin**. Next we'll go to Henry Brown, from Greenville, South Carolina, and for that introduction I will yield to my distinguished colleague from South Carolina, Senator Thurmond.

Senator **Thurmond**. Thank you very much, Mr. Chairman.

Mr. Chairman, I would like to commend you for holding this hearing on the Developmental Disabilities Act. Although I am not a member of the Subcommittee on Disability Policy, I am most interested in helping those with disabilities to lead meaningful, independent lives and to be productive citizens.

It is a pleasure for me to introduce Mr. Henry Brown of Greenville, South Carolina, who will be presenting testimony today. Mr. Brown is appearing as the parent of an adopted child who has developmental and emotional disabilities. Mr. Brown is also the Chairman of Protection and Advocacy of Individuals with Retardation, which is referred to as PAIR. This organization serves as an advisory group to the South Carolina Protection and Advocacy System.

I am confident that the members of this subcommittee will benefit from the testimony of Mr. Brown concerning the Developmental Disabilities Act and its relationship to the Protection and Advocacy System in the United States.

Mr. Chairman, my schedule will not permit me to remain for the entire hearing—in fact, I am in another committee meeting now that I will have to return to. However, I shall review that testimony that is presented with interest.

Thank you very much.

Mr. Brown, we are delighted to have you here.

Senator **Harkin**. Mr. Brown, welcome, and please proceed.

Mr. **Brown**. Thank you, Senator Harkin, for inviting me, and Senator Thurmond for the introduction.

It has been 15 years since I've been to Washington, and I can't think of a better reason to come back than to speak about the reauthorization of the DD Act.

I'd like to address the committee from two perspectives—one, personally, as how the P&A System has benefited our adopted daughter and our family, and then second from my perspective as the chairman of PAIR.

In 1984 my wife and I adopted two siblings who prior to their adoption had been separated for 6½ years. Debbie, the younger daughter, had been in the same foster home for that entire time. Donna, the older daughter, who was dually diagnosed, had seven foster placements between the ages of 5 years and 12, when we adopted her.

Of course, it was her behaviors and problems which created the multiple placement. We entered the adoption with open eyes, thinking that we both because of our backgrounds—I am a certified rehabilitation counselor, my wife is a special ed teacher just completing her doctorate in special ed administration—that we could handle and meet the needs of these girls. We have been excited about the accomplishments and progress that has been made, particularly when Donna has been with us.

But during the three and a half years that she was with us before an alternative placement—and that was the longest time that Donna had been in any one type of placement—of course, we had to deal with the acting-out behaviors. We secured the services of mental health treatment, of the adolescent program in the county. But by the time Donna was 15, we could see an escalation and realized that we needed more specialized treatment and began to look for help. We made over 35 contacts, for either therapeutic respite, long-term treatment, specialized counseling, and nothing was available.

Finally, it had escalated to the point where, because I felt for the mental health of Donna and her sister and our family that something had to be done. I will just give one instance that really brought this to my attention was the fact when I could no longer send her to her room for "time out" and so she had to be in the room with us whenever we had a "time out" situation, and she began destroying things and holding her arm, so she wouldn't hit her sister or other things, for two hours while she was hitting my face—I realized I had reached my limit, and something drastic had to be done.

We had her admitted to Patrick Harris State Mental Hospital. After they evaluated her, of course, they said that it was not an appropriate placement, and we agreed that it was not an appropriate placement. But I decided that I would not take Donna home until the appropriate treatment and appropriate availability of services were available for her sake, and I stood my ground.

The hospital said, well, we will discharge her, and you will be charged with neglect by the Department of Social Services. They made that attempt, and when Social Services got involved in the case, they backed out right quick, because we had thorough documentation—I had even recommended a respite treatment program that I felt was reasonable and felt could be established, but the agencies did not want to work together to do that.

We did contact the Department of Mental Retardation and the Department of Mental Health. She was declared eligible for services for those programs. There is a special program called the Continuum of Care, and she was declared eligible for those services. So we felt excited. Every one of these people agreed she needed help, and she was eligible. But nothing happened because they would not agree as to who was the primary service provider and what the funding allocation would be. So nothing happened.

It was at this point that we contacted the P&A System because of the lack of services, the inappropriate placement of Donna, and at that time, the concern of being charged with neglect, which could affect both of our jobs professionally.

Prior to contacting P&A, our view was that there was a complacency about the lack of service by the agencies. They readily acknowledged the eligibility, but there was very little concern about trying to come up with something new or to look and see if services could be provided. There was no specific effort to coordinate with other programs to provide services.

We felt that there was kind of an attempt, subjectively, to impart guilt to us for putting our daughter in such an inappropriate placement. But we felt that to get the services that she needed long-term, we had to do that.

Well, when P&A became involved, all of a sudden they began to seriously listen, and P&A was the catalyst to bring about the meeting between the Department of Mental Health, the Department of Mental Retardation, Continuum of Care, Department of Education. And even after they forced the meetings to get together, there was still this hassle—who is going to do what? And finally, after exhausting all the due processes, the P&A System finally was able to get us before the CCRS, the Children's Case Resolution Services, which is a committee in the governor's office, which is an arbitrator when this happens between agencies. The CCRS says, "You do this, you do that, and you pay that much."

So now Donna is in a community residence, is attending a local high school, and again, with P&A's help, is in a job training program to prepare her for independent living in the future.

To summarize, I think the impact of P&A was important number one in helping us to know specific legal rights of due process and specific responsibilities. My wife and I, both being professionals in the area, had a good general idea of the law, but we found out that if the agencies know that you don't know what they are supposed to do, they don't do it.

So, I began to find out what they were supposed to do, and P&A was a great help in that. They were important in causing the agencies to begin to work together and to provide services.

The concerns that we had after we sat back and reflected about this were, number one, without the help of P&A, our daughter would be in worse shape. She spent 10 months in this State hospital. During those 10 months, she digressed significantly in education. Donna had come from being below second grade level in reading to just about the fourth grade level when she went into the hospital. She had learned her multiplication tables, and she was, we felt, a long way toward becoming independent. Now we have noticed when she visits every other weekend, her reading level has significantly decreased—all of these things because there was a minimal education program. And I think without the help of P&A, she would still be in that predicament, or I would be in jail, probably one of the two.

We as professionals knew where to go. We knew to contact the P&A. And it concerns me now as I have looked back—what do people do who do not know where to go? I think serious consideration needs to be give to requiring agencies with funding to do so to provide the clients that they serve information about the P&A. I would go further to State require that the family be put in contact with the P&A service provider. I know that means more work and more funding, but I think for the rights of these children to be served. And now I am more aware, and I come across people who are not receiving services. And I ask, "Have you contacted the Protection and Advocacy System," and they say, "No, we didn't know about it." And yet they may have been in class in special ed for years, and so forth.

Then, as a chairman of PAIR and now being involved in the process of PAIR, one thing that concerns me is the lack of funding has caused turnover of the legal staff and case managers, and it means retraining. That is something that our PAIR subcommittee worked on with the P&A board—keeping qualified people on staff who have the expertise, and then when you get them trained, a government agency or another agency that pays higher snatches them off. It is the children and people with developmental disabilities who are really deprived when you have inexperienced workers while they are learning.

Then last of all, a concern that I have—and I feel very strongly about this—is that P&A be an independent agency. After seeing the response of the agencies, I would be frightened to think what would happen if the P&A were controlled by any State agency or State office. They need to be outside as a watchdog agency. I feel very, very strongly about that.

Thank you for letting me be here today. I appreciate the work you all have done in behalf of developmental disabilities.

Senator HARKIN. Mr. Brown, thank you very much for that excellent testimony. Did you say it has been 15 years since you have been to Washington?

Mr. BROWN. Yes, sir.

Senator HARKIN. When was the last time you testified before a committee?

Mr. BROWN. I have never testified before a Senate hearing.

Senator HARKIN. Well, gosh, I thought maybe you did this every week the way you rolled that out.

Mr. BROWN. Well, I do a little preaching on the side. [Laughter.]

Senator HARKIN. Well, it was great testimony.

Mr. BROWN. In North Carolina I testified in a court situation with education, and they asked the wrong question, and I got going, and the judge said, "This is not a pulpit."

Senator HARKIN. Well, this is a pulpit, so you can go right ahead.. [Laughter.]

[The prepared statement of Mr. Brown follows:]

PREPARED STATEMENT OF F. HENRY BROWN

INTRODUCTION

Senator Harkin, I wish to thank you for inviting me to address the Subcommittee on Disability Policy concerning the Developmental Disabilities Assistance and Bill of Rights Act Amendments of 1987. I am honored to be from the great Southern state of South Carolina which is represented on the Committee on Labor and Human Resources and the Subcommittee by our Honorable senior Senator from South Carolina, Strom Thurmond.

The Developmental Disabilities Assistance and Bill of rights Act has four components: the basic State grant program; the protection and advocacy systems; the university affiliated programs; and special projects. I am here today to speak specifically in regards to the component of the Developmental Disabilities Assistance and Bill of Rights Act which relates to the protection and advocacy systems. I would like to address this issue from two perspectives: 1) The benefit of The South Carolina Protection and Advocacy System to my wife and me in helping to secure appropriate services for our adopted daughter who has a developmental handicap; 2) As chairperson of PAIR (Protection and Advocacy for Individuals with Retardation), an advisory committee to the S.C. Protection and Advocacy System.

THE BENEFIT OF S.C.P.& A. TO OUR DAUGHTER

In April 1984 two sisters, ages 11 & 12, named Debbie and Donna came to live with us, with the intentions of our finalizing adoption after a years residency with us. A year later the adoption was finalized. Prior to coming to live with us, Debbie and Donna had lived apart in separate foster homes for the past 6 1/2 years. Debbie had lived in the same foster home for the entire period, but was reunited with Donna in October 1983 after her foster mother died. Donna, the older sister, had seven foster placements from the time of age 5 up to the time of arrival at out home. Donna has mental retardation and is also dually diagnosed as having an emotional handicap. Prior to coming to live with us, Donna had been on Ritalin 365 days per year. Both of natural parents have mental retardation and the natural mother also has familial history of mental illness. Debbie and Donna were removed from their home at the ages of 4 years old and 5 years old because of neglect by the parents and inability to control Donna's behavior.

Over the years Donna has a learned behavior of getting out of responsibilities by exhibiting abnormal non-compliant behaviors by hollering, throwing items, hitting individuals close to her, and destroying personal property. These behaviors were also accompanied by frequent incidences of lying and stealing. after arriving at our home, Donna manifested all these behaviors. This resulted in our having to put a dead bolt lock on our bedroom, where we also had to store all food stored in box containers. We also had to put a lock on the refrigerator. Donna would eat whole boxes of cake mix, brown sugar, toppings, etc. We had her evaluated for Prader-Willie Syndrome, but the results were negative.

After three years these behaviors become too disruptive for our family, even though we had been receiving therapy for Donna and the parents twice a month for nearly two years. We had Donna evaluated at Marshall Pickens Psychiatric Hospital for a period of 30 days (which used up the lifetime maximum of psychiatric benefits) where they recommended that Donna be in a structured program with a strong emphasis on behavior management.

While in the program at Marshall Pickens Hospital, we began inquiring about available services, making over 35 contacts to specific programs and agencies. Donna was declared eligible for services by the South Carolina Department of Mental Retardation, The S.C. Department of Mental Health, and the Continuum of Care (a special program for emotionally handicapped children). However, because of being both developmentally disabled and emotionally handicapped, Donna did not have a specific program to meet her need. It was as though each program regarded one of the other programs as having the major responsibility of providing services and funding such services. The end result was that no services were being provided. When Donna came out of Marshall Pickens Hospital, we had not located any available program; therefore, we had her committed to Patrick Harris Hospital in the adolescent unit. After she had been there for 21 days they informed us that she did not have a psychotic condition; and that this was not the best place for her. We agreed with them, but also stated that we would not take her back home without appropriate therapeutic respite services available.

It was at this time that we contacted the S.C. Protection and Advocacy System about Donna being inappropriately placed at Patrick Harris Hospital, but also being unable to return home without proper services available. It was through S.C.P.& A.'s work that all the agencies involved finally agreed to sit down and work out a program of treatment and agreement of funding for this treatment. Even with S.C.P.&A.'s intervention, Donna still spent 10 months in Patrick Harris Hospital. This long stay in a mental institution caused a regression of educational achievement that she had made for the previous two years while at home; cause the educational program at the institution was a minimum program. Without the S.C.P.& A.'s help, we would have never, our opinion, received treatment for Donna. She is now in a residential program with five other girls. We have a long range goal of her being able to live in an independent supervised living program operated by the Greenville Association for the Retarded.

My wife and I are both professionals in the areas of special education and rehabilitation counseling, and it was difficult for us to receive proper services for our daughter even though we knew the laws about serving individuals with handicapping conditions and knew what individuals and agencies to contact for services, and knew how to aggressively advocate for our daughter. We have both commented on what do families do who do not have our training? It is imperative that funding for Protection and Advocacy Systems be maintained to advocate for individuals with developmental disabilities. Our experience is that agencies will generally do that which is most convenient and least expensive for them rather than what is appropriate and best for the individual being served.

THE WATCH DOG MUST NOT BE A PART OF THE AGENCY. Our experience here in South Carolina reflects the experience of P&A's throughout the country that in order to do our work , the agency must be independent of the service providers and must be free to agressively advocate on behalf of our children.

THE BENEFIT OF S.C.P.& A. TO PAIR

S.C.P.& A.'s observance of our aggressive advocacy for our daughter resulted in their inviting me to be a member of PAIR. After becoming a member of PAIR, the other members elected me to be the chairperson of this advisory committee to S.C.P.& A. Since being a member of PAIR, I have been made aware of the very important roles that S.C.P.& A. has in the state of South Carolina in prompting agencies to provide appropriate, available services and prompting the legislature in funding such services or creating legislation which require that services be provided. Most of this is done without having to resort to litigation, because the agencies and the legislators respect the opinion and the advice of the S.C.P.& A. However, when necessary S.C.P.& A. will instigate litigation to insure that an individual receives the services to which he or she is entitled. P&A's around the copuntry continue to solveproblems with the least amount of formal intervention partly as a result of having the ability to use legal remedies if the system refuse or is unable to respond to the needs of persons with developmental disabilities. Without the Protection and Advocacy Systems in our Country, individuals with developmental disabilities would not receive those services to which they are entitled by law and which would enable them to become more independent and have a better quality of life.

However, the limited resources of the P&A system are stretched beyond the ability to serve all those who need this assistance. In addition to those waiting for community services siumilar to those need by our duaghter, the P&A is struggling to meet the needs of persons who are developmentally disabled who reside in nursing homes, state insititutions, state schools, board and care homes, and prsions. As chairperson of PAIR (PROTECTION AND ADVOCACY FOR INDIVIDUALS WITH RETARDATION) representing all of its members, we urgently ask the members of the Committee on Labor and Human Resources to continue the funding of the Developmental Disabilities assistance and Bill of Rights Act

Amendments of 1987, and to specifically increase the support for the Protection and Advocacy Systems throughout the country to meet the demands of the new civil rights protections pending in Congress.

The citizens with disabilities of South Carolina thank you for your leadership in protecting their rights.

Senator **Harkin**. Next we will hear from Dr. Healy, Director of the Division of Developmental Disabilities at the University of Iowa. He is a distinguished pediatrician a the University of Iowa; holds academic appointments in the Department of Pediatrics and the Department of Special Education. He is past president of the American Association of University Affiliated Programs. He is recognized internationally and is often invited for consultation to organizations serving people with mental retardation and other disabilities in other countries.

He is accompanied today by Kim Hurley, whom I just met this morning, from the University of Northern Iowa. She is testifying as a consumer on behalf of the American Association of University Affiliated Programs.

Kim is 20 years old and has cerebral palsy. She uses both an automated wheelchair and an assistive speech device. As I said, she is a student at the University of Northern Iowa, studying accounting. And my notes tell me she drives to school in a Volkswagen. Well, the driving to school is significant; I don't know what significance the Volkswagen is. [Laughter.]

But thank you both for coming, and Dr. Healy, please proceed.

Dr. **Healy**. Thank you very much, Senator Harkin.

As you indicated, I am Director of the University Affiliated Program at the University of Iowa. I would like to join in the tenor of this meeting and point out to you that two of my children have been educated in Iowa and now are residents of Minnesota. [Laughter.]

Senator **Harkin**. When Senator Durenberger comes back, we'll tell him that.

Dr. **Healy**. As you have indicated, Kim Hurley is with me—a young lady in whom I take tremendous pride in that she has utilized the services of the Iowa University Affiliated Programs since she was an infant and has parlayed those services into what I believe is a tremendous life, and she will share with you some of her aspirations and dreams in a little bit.

Before I get into the specific testimony, I'd really like to thank you, Senator Harkin, for the tremendous assistance that you have provided—not only the entire DD network through your legislative efforts, but specifically on behalf of the University Affiliated Programs. Prior to your assumption of the chair, increases in appropriations and responsibilities could be described as somewhat minimal. Since your involvement, they have had at least some substantive increase in our appropriations.

Borrowing a term from Elizabeth Boggs which she has used in some of her previous testimony, our appropriations represent "decimal dust" for OMB, and we would like to see on behalf of the entire network significant increases in that appropriation if that could be possible.

Turning to our specific recommendations to you committee, I'd like to propose a modification of the legislative provisions controlling the expansion process while we have the whole concept of emphasizing quality to you.

Recognizing the needs to expand the benefits of the UAP program to all 50 States, while yet concerned that applications be judged on their merits, we have proposed a broad series of factors that the Administration on Developmental Disabilities may use in judging applications from interested universities. The net effect of these recommendations is to permit institutions of higher education from States already served by UAP's to apply.

This approach would accomplish two important objectives. First, it would re-establish programmatic quality as the single most important criterion in determining whether a new UAP should be funded. Second, this approach may prove effective in addressing the training and service requirements of disability populations whose current needs are not being met either because of the sheer physical size of a particular State or its overall population density. This concern includes those States with low population densities not currently being served.

When we move to the areas of early intervention, aging and paraprofessional personnel preparation, we have proposed the creation of a new permanent training core award. Our principal concern is continuity. The early intervention program under Part H, which you championed in 1986, is a good illustration of this need.

The Office of Special Education Programs recently projected that 100,000 infants and toddlers with disabilities will be eligible to receive services under this Act beginning next year. This figure may be even a gross under-estimate, particularly in view of the large number of drug-exposed babies being born into our inner cities every day who all have the potential to experience significant developmental delays or disabilities.

I want to assure you that even our State of Iowa is not immunized against this problem. We are seeing and will continue to see an increasing number of so-called crack babies and others who are the result of pregnancies of addiction.

But while we as a Nation have made extraordinary progress in erecting Interagency Coordinating Councils and establishing State policies to ensure that these children receive early intervention, we simply do not have the trained occupational therapists, physical therapists, speech pathologists and other personnel actually needed to provide the services.

Over 85 percent of the States report significant deficiencies in the numbers of qualified personnel. However, in issuing 14 early intervention training grants to the UAP network, ADD provided for only two-year grant periods. The current recompetition of these same grants also envisions a two-year award cycle. Let me assure you, Mr. Chairman, that the early intervention personnel needs of this country will not be resolved over the next 24 months, as you well know.

In order to keep our collective promise to these infants, Congress, the Department of Education, ADD and the UAP national network have got to stick to it over the long haul. The need for continuity in preparing direct care staff for work in community-based residential programs and training health professionals in providing services to elderly persons with developmental disabilities is equally critical.

At the same time, consumer and advocacy organizations, as you have just heard, recognize that there are additional training needs in such areas as positive behavior management, as eloquently brought out by Mr. Brown just recently, State-based training, assistive technology, prevention of disabilities, and children with HIV infection.

For example, we firmly believe that a critical element in maintaining persons with disabilities in the community as well as facilitating their transition out of institutional settings it the provision of proper behavior management training to direct care staff. This is an important issue now on the agenda of the Iowa University Affiliated Program, as it is in many other UAP's across the country.

We have heard information from Dr. Lakin on this subject.

Finally, Mr. Chairman, the AAUAP is seeking a small increase in the core administrative award for each UAP. These administrative awards are important because they constitute the glue that keeps us together. Representing a farm State as you do, you are acutely aware of the need for pre-production financing of such things as fertilizers, pesticides, and equipment—costs that must be carried before the first seed can be planted, let alone before the crop can be harvested.

Core administrative funds cover roughly these similar costs and retain a high potential to continue producing bountiful harvests for persons with disabilities.

Overall, the UAP's are one of the best investments the Federal Government has ever made, and I am firmly personally convinced of that. In fiscal year 1989, it got back $21 for every dollar it put into the UAP network. At the University of Iowa, the $200,000 ADD core award yields a total program budget which exceeds $8 million.

But despite the fact that administrative costs keep rising, the UAP's have received one small core award increase since 1975. A continuation of this funding pattern will almost certainly jeopardize these programs in the long run. We continue to ask the universities to keep providing us with the additional resources to meet our growing needs, and this just cannot continue. It is our hope that you will give our request due consideration.

Once again, Senator Harkin, Kim and I appreciate this opportunity to appear before you and the committee, and we thank you for your continuing support.

I would point out to you that Kim is going to use a real voice synthesizer because she has a speech impairment. We often look upon the statement "speech and language" as one word. They are very distinctly different functions.

Kim has exquisite control of the English language; she has difficulty in expressing herself using the oral expressive language. She expresses herself considerably well using technology and the written word through other computerized methods.

Thank you, Mr. Chairman.

[The prepared statement of Dr. Healy follows:]

PREPARED STATEMENT OF THE AMERICAN ASSOCIATION OF UNIVERSITY AFFILIATED PROGRAMS FOR PERSONS WITH DEVELOPMENTAL DISABILITIES ALFRED HEALY, M.D., ON BEHALF OF

Good morning, Senator Harkin, my name is Alfred Healy and I am the director of the Iowa University Affiliated Program located at the Hospital School on the University of Iowa campus. With me at the witness table this morning is Ms. Kim Hurley. I have known this young lady since she was a infant and she has used many services available through the Iowa UAP. Kim is now a student at the University of Northern Iowa where she is an accounting major, drives a car, and despite her mobility and speech impairments, she is as independent as any other undergraduate on campus. I take personal pride in her many achievements and we thank you for inviting her here today.

Before I begin a substantive discussion of the legislative proposals for the University Affiliated Programs (UAPs), I wish to convey a word of thanks. As you well know, UAPs are primarily organizations that provide interdisciplinary training and exemplary services on behalf of persons with developmental disabilities. Training is not a very sexy issue, either on Capitol Hill or in many state capitals for that matter.

Yet, Senator Harkin, you and your committee have stood virtually alone in your support for qualified, well trained health professionals to provide services to persons with disabilities. Since you assumed the chairmanship of the Subcommittee on Disability Policy, six new UAPs have been created -- the largest single expansion of the network since the DD Act was created in the carly 1970's.

Moreover, for the first time, significant additional resources were provided to the UAPs to conduct substantive training initiatives in the areas of aging, early intervention and paraprofessional personnel preparation. In view of this extraordinary record of achievement, the entire membership of the American Association of University Affiliated Programs (AAUAP) wishes to express its heartfelt appreciation. Persons with disabilities in the State of Iowa and across the country have been the principal beneficiaries of your courageous leadership.

EXPANSION

In turning to our specific recommendations, AAUAP has established expansion of the network as its top priority. However, we are proposing a modification of the legislative provisions controlling the expansion process, which will have the effect of emphasizing quality.

Recognizing the need to expand the benefits of the UAP program to all 50 states, while yet concerned that applications be judged on their merits, we have proposed a broad series of factors that the Administration on Developmental Disabilities (ADD) may use in judging applications from interested universities. The net effect of this recommendation is to permit institutions of higher education from states already served by

UAPs to apply. This approach would accomplish two important objectives. First, it would reestablish programmatic quality as the single most important criteria in determining whether a new UAP should be funded. Second, this approach may prove effective in addressing the training and service requirements of disability populations whose current needs are not being met either because of the sheer physical size of a particular state or its overall population density. This concern includes those states with low population densities not currently being served.

EXISTING TRAINING PROGRAMS

In the areas of early intervention, aging and paraprofessional personnel preparation, we have proposed the creation of a new permanent training core award. Our principal rationale is continuity.

The Early Intervention Program under Part H of the Education of the Handicapped Act (EHA), which you championed in 1986, is a good illustration of this need. The Office of Special Education Programs (OSEP) recently projected that 100,000 infants and toddlers with disabilities will be eligible to receive interdisicplinary early intervention services when Part H is implemented in the 50 states next year. This figure may be a gross underestimate, particularly in view of the large numbers of drug exposed babies being born into our inner cities everyday who ALL have the potential to experience significant developmental delays or disabilities.

But while we, as a Nation, have made extraordinary progress in erecting Interagency Coordinating Councils and establishing state policies to ensure that these children receive early intervention, we simply do not have the trained occupational therapists, physical therapists, speech pathologists and other personnel to actually provide the needed services. Over 85% of the states still report substantial shortages in each of these critical disciplines.

However, in issuing 14 early intervention training grants to the UAP network, ADD provided for only a two year grant period. The current recompetition of these same grants also envisions a two year award cycle. Let me assure you, Mr. Chairman, that the early intervention personnel needs of this country will not be solved in next 24 months. In order to keep our collective promise to these infants, Congress, the Department of Education, the Administration on Developmental Disabilities and the UAP national network have got to stick to it over the long haul. The need for continuity in preparing direct care staff for work in community-based residential programs and training health professionals in providing services to elderly persons with developmental disabilities is equally critical.

NEW TRAINING INITIATIVES

At the same time, consumer and advocacy organizations within CCD recognize that there are additional training needs in such areas as positive behavior management, state-based training, assistive technology, prevention of disabilities and children with HIV infection.

For example, AAUAP firmly believes that a critical element in maintaining persons with disabilities in the community as well as facilitating their transition out of institutional settings is the provision of proper behavior management training to direct care staff. No doubt, will hear additional testimony on this topic from Dr. Lakin.

UAP CORE ADMINISTRATIVE AWARD

Finally, Mr. Chairman, AAUAP is seeking a small increase in the core administrative award for each UAP. These administrative awards are important because they constitute the glue that keep our programs together. Representing a farm state as you do, you are acutely aware of the need for pre-production financing of fertilizer, pesticides and equipment costs that must be carried before the first seed can be planted, yet alone before the corp can be harvested. Core administrative funds cover roughly similar costs and have the high potential of producing a bountiful harvest for persons with developmental disabilities.

Overall, the UAPs are one of the best investments the federal government has ever made. In FY 1989, it got back 21 dollars for every dollar it put into the network. At the University of Iowa, the $200,000 ADD core award yields a total program budget which exceeds $8 million.

But despite the fact that administrative costs keep rising, the UAPs have received one small core award increase since 1975. A continuation of this funding pattern will almost certainly jeopardize these programs in the long run. We continue to ask the ~~cannot expect the~~ universities to keep providing us with additional resources to meet every growing needs while the federal contribution remains stagnant. Its our hope that you will give our request due consideration.

Once again, Senator Harkin, Kim and myself appreciate this opportunity to appear before you. Thank you for your continuing support. I am prepared to respond to any questions you may have.

Senator **Harkin**. Kim, we are delighted to have you here. Please proceed.

Ms. **Hurley**. Hello. Good morning. My name is Kimberly Hurley. I am from Volga, Iowa, and I am a student at the University of Northern Iowa. I am honored to have this opportunity to share my personal determination to be independent with you this morning.

In my viewpoint, we are here today to focus on assisting our many Americans with disabilities to strive to be as independent as they can be. Independence is the key to reaching an individual's fullest potential for their own self-motivation as well as to take an active role in society.

I have had cerebral palsy since birth. I was an inpatient off and on for seven years at the Iowa University Hospital School, Iowa's University Affiliated Program.

While staying there for intervals of up to seven weeks, I received physical, occupational and speech therapy. This therapy was continued when I returned to my public school at home. In school, I have witnessed numerous students with disabilities being guided and taught to use adaptive devices and modified techniques which aid them in performing daily tasks.

Over the years, a variety of devices have had to be purchased to facilitate me in my goal for complete independence. Easter Seals, Vocational Rehabilitation and Social Security have assisted me to acquire devices such as a motorized wheelchair, a portable computer as my means of writing, and this voice synthesizer for communication.

These devices, particularly my voice synthesizer, have helped me to broaden my horizons by belonging to my high school's newspaper staff; a 4-H club in which I did presentations and took an active part in community service projects; and two years of studying and speaking a foreign language; I also was a member of my school's Spanish Club.

I discovered that I really could be a successful job holder when I was hired through JTPA for a position at a museum two summers ago. Without this financial aid, coupled with the technical assistance of the Iowa UAP, it would not have been possible for me to obtain these devices which help me to be integrated with society.

After graduating from high school last year, I chose to further my education in accounting at the University of Northern Iowa. I am living independently in a campus dorm.

My independence proves that I can conquer almost anything which I set my mind to. I could not have come this far if I didn't receive the medical and educational services which were provided through financial aid. If we want equality in this country, it is our duty to strive for the independence of every individual which they deserve.

The more independent a person is, the greater capacity he or she can benefit society. With the ability to perform at an adaptable job, an individual is a taxpayer, which benefits the economy as well as becoming a remarkable asset to our country as a whole. To take an active role in society is to make a person's dream to become independent come true.

Thank you.

Senator HARKIN. Very good. That's the best voice synthesizer I have heard yet. I mentioned that to my staff and they said that's because that is one of the first that utilizes a woman's voice. And I just recognized that; that is right. It is the first one.

Dr. HEALY. That's right. It came out two years ago. And Kim has refused to use one that had a male voice or a child's voice.

Senator HARKIN. Good for you. That's great.

Can I ask how much something like that costs? You are in accounting. Can you tell me how much that costs?

Ms. HURLEY. Twenty-five hundred dollars.

Senator HARKIN. Wow. Who pays for it? Did you have to pay for it? That's a lot of money. Who pays for something like that? Did you have any assistance?

Mrs. Hurley. We had assistance from her local 4-H Club, and Lutheran Brotherhood matched funds to get this.

Dr. HEALY. It emphasizes the need, as you previously brought out, relating to the Technology Assistance Bill for the purchase of the hardware.

Senator HARKIN. Absolutely. That's wonderful.

Now, Kim, do you use the voice synthesizer in your classes at school?

Ms. HURLEY. Yes.

Senator HARKIN. Now, when you prepare a lesson, like in your dorm at night, you can go ahead and program in responses for a lesson, let's say, that you are preparing the next day?

Ms. HURLEY. Yes.

Senator HARKIN. Will this help you to interact with—well, I guess you're interacting with me right now. Why do I have to ask a question like that? [Laughter.]

I was just thinking about how you would interact with the professors and so on, and of course, this enables you to directly interact.

Ms. HURLEY. You can never shut me up. [Laughter.]

Senator HARKIN. You also have a great sense of humor. Well, we are delighted to have you here. You have brightened our day. That is wonderful.

Kim, it really is wonderful to have you here and see how much you have progressed, and it really is exciting to see how you have been able to use technology to help you accomplish the same goals as any young person your age who is intelligent and determined to succeed.

Could you tell me basically what your dream really is? Here you are, you are a young person, you are in college, you are doing very well. You have got some barriers. You have got some obstacles to overcome. Obviously, you have overcome a great deal of them. What are you looking forward to? What are your hopes for your life, personally and professionally?

Ms. HURLEY. My dream is to become a successful C.P.A., without barriers of any kind. In order for this, there must be something to tear down visible barriers as well as end discrimination—to be the best I can be.

Senator HARKIN. That's great. Do you like accounting?

Ms. HURLEY. Yes.

Senator **Harkin**. Do you like working with numbers and things like that?

Ms. **Hurley**. Yes.

Senator **Harkin**. Good for you. That was never my strong point. [Laughter.]

As I have always said—somebody's got to take care of the numbers around here.

Dr. Healy, let me just ask you a question—oh, I'm sorry; Kim's got something else coming here.

Ms. **Hurley**. I have one up on you.

Senator **Harkin**. Yes—you probably have a lot more than one up on me. That's very good. As I said, you have brightened our day, and I appreciate you being here.

This is your first trip to Washington. Are you going to be here for a couple of days?

Ms. **Hurley**. Yes.

Senator **Harkin**. And you have your mother and your sister here. Well, make sure you get around to see all the monuments and things—as I said, make sure you come up to my office later, and we'll get you lined up for all that.

Dr. Healy, you were talking about what success the UAP's have had in leveraging their Federal dollars as a means of carrying out their mission. Can you tell us, based on your experience in Iowa and your knowledge of UAP efforts in other States, how successful UAP's have been in using their Federal dollars to attract funding from other sources? Now, what was that figure you used, again?

Dr. **Healy**. I had previously mentioned that the core administrative award to the University of Iowa UAP is $200,000. The net programmatic funding for all of the services through the Division of Developmental Disabilities, of which the UAP is an integral part, is $8 million. So the core basic award allows us to use the expertise available to go out and garner additional both State and private foundation dollars to support the needs of children and young adults such as Kim.

It is both in the areas of service, teaching, training, provision of technical assistance, and provision of information to those who need the specialized technical knowledge to assist person's such as Kim through their life's work.

We have been successful in the State of Iowa. It is a relatively asymmetrical pattern throughout the United States. Others have not been as successful. We have a particular State that has found itself in a position to support our program. Other States have not been so fortunate.

I believe there is an absolute need for us through this administrative core award, including potential, as you are aware, increases in training core awards that these can be parlayed into considerable nonFederal assistance into the programs.

Our experience to date relating to the training initiatives would suggest that the training initiative is allowing us to match dollar-for-dollar for external nonFederal funds. That is the initial information we have available from the first two-year grant cycle.

Senator **Harkin**. Mr. Brown, again I appreciate your statements on the watchdog must not be part of the agency. I talked about that earlier with Deborah. Again, I assume that you feel it is very important that the P&A Systems be independent to advocate effectively.

Mr. BROWN. I think it would compromise the effectiveness of P&A if they were made a part of or under the direct authority that could affect them politically or bureaucratically as to the actions they make and the decisions and recommendations that they make.

Senator HARKIN. You are familiar with the Americans with Disabilities Act that is coming down the pike.

Mr. BROWN. Yes, sir. I am the director of a multihandicapped residence for individuals with mental retardation. This is a new residence in our State, and we have orthopedically handicapped, deaf and blind residents. I am very much aware now—I hadn't thought about it, but when we go out into the community now, it has impacted more on our residents as they go out and function—of how much we need that for them to be integrated into the community and to have access.

Senator HARKIN. I just wonder what the impact of that will be on the P&A System.

Mr. BROWN. I think it is going to bring a need for greater advocacy both in numbers, and that is why I think the former testimony about level funding which you were directing upon to meet the greater needs—I don't see how they can do it. I think it is kind of short-sighted on the Administration's part not to look at that. If they are also pushing for the passage of the Disabilities Act, they also need to be prepared to see that these services and rights are ensured and that there is someone there to represent these individuals. And that has got to be funded to make sure this is carried out.

Senator HARKIN. Well, I agree with you. I just think that with the passage and signing of the ADA bill, which will happen soon, that there is just going to be much more demand for services because people are going to demand their rights.

Mr. BROWN. And they have a right.

Senator HARKIN. And they have a right to demand that, you bet they do.

Mr. Campbell, we heard in your testimony about the barriers that are created in a complicated system of services; you went through that pretty well about how complicated these things can get. Families, in all too many instances, obtain the services in spite of the system; they just bowl their way through it in one way or another.

The Consortium for Citizens with Disabilities is recommending an expansion of the priority area previously titled "case management". Could you tell the committee what new directions this proposed change might offer for the Councils and other programs created by this Act?

Mr. CAMPBELL. I think we are in a situation where we can attempt to address a number of these items currently, but we don't have a clear indication of support for a new initiative. The findings of the 1990 reports will I think be most easily implemented if we have a priority which allows us the flexibility to deal across agencies and to allow for better coordination amongst agencies and their intricacies so that they become supportive, so that they are not continually adversarial with people's goals in terms of agencies should exist to be supportive of the needs of the individuals that they exist to serve. We continually find that agencies, because of their eligibility requirements, because of restrictions in how far they can go with what individual and in what direction, create more barriers than they solve for people who already had a problem or they wouldn't be seeking services from the agency.

We feel that a priority allows us to look at cross-cutting issues amongst a variety of agencies and allows us to bring resources to bear to permit services to be rendered in a supportive manner to people is the essence of what a new priority would do for us.

Senator **Harkin**. All right. Is there anything anybody would like to add before I conclude this? Does anything come to mind that you thought, "I should have said this and didn't say it"?

Mr. **Brown**. I think a wise allocation of money, in reading through the Developmental Disabilities Act and the Bill of Rights, is the fact of greater emphasis on family support—for example, in our situation, I recommended a respite-type treatment program which I felt would have been much more cost-effective than what is being provided. And I think depending on where the moneys are and where the emphasis is given that what is being done is great, but we could have used the money more wisely. If the emphasis could be funding for family support services, it would decrease the waiting lists, it would decrease having to use institutional or other services. So I'd like to see funding for real impact upon those services.

Dr. **Healy**. If I may interject and just suggest in a summary way that I think every witness this morning would join with me in thanking you personally for leading a very courageous fight in behalf of persons with disabilities, not only in the reauthorization of this activity but in the Technical Assistance Bill and the Americans for Disabilities Act and the services for the deaf and NIH, everything that you have done, we thank you from the bottom of our hearts.

Senator **Harkin**. You are very kind to say that. [Applause.]

Thank you for that, and I appreciate all of your warm responses on that. But it is not just me. So many have come before me—I'm thinking of people like Lowell Weicker, who dedicated a lifetime of work to this; Senator Durenberger, others on the full committee as well as on the subcommittee, on both sides of the aisle, but especially the people who are sitting behind me here—the staff—who have really done such a great job of making sure we get this done. Too often those of us who have the elective office get the accolades, but more often than not the unsung heroes are the staff, who really do the work and make sure we get it through. So I just want to publicly thank all the staff who are here on both sides—I'm not singling out one side or the other—both sides, who have worked so hard to make sure we get these pieces of legislation through, and I must say also, making sure that we keep on the Administration and make sure we get the proper rules and regulations going, too.

But you were kind to say that, and I appreciate it very much.

Kim, or any of you, have you seen "My Left Foot" yet? I don't think it has been in Iowa yet, but you've got to see it. Has anybody out there seen it—yes, some of you have seen it. It is a great movie, and I was really glad that that guy won the Best Actor Award, and also, the woman won the Supporting Actress Award for that movie. It is a great movie and one I hope that millions of Americans see—you might think I have stock in that movie. I don't. I just think again it really brings home to you that while you may have one obstacle in your life, that does not mean you are restricted in any other area. Obviously, a very bright, capable person—I thought one of the best parts of the movie was when his father went back to that tavern after his son had written on the floor with his foot; and he runs into the tavern and says, "My son is a genius." That was one of the best parts.

Developmental disability policy and services are singularly unique in this country in that they have largely been shaped by consumers, their families and the advocates. Their ranks have been joined by researchers and professionals from a wide range of disciplines. Substantial progress has been made during the last 25 years toward the prevention, early intervention and amelioration of developmental disabilities and the creation of opportunities for people with disabilities to live, work and play as equal members of society.

The programs authorized by the DD Act have been instrumental in creating the capacity for all members of the disability community to work together for the advancement of independence, productivity and integration for people with developmental disabilities.

And one of the priorities of being the Chair is that I always get to have the last word—and the last word is to repay you in kind for what you just said about me and to thank all of you who have devoted lifetimes of work to this, to making sure that we have not only a caring and compassionate society, but a society that meets the obligations of providing the opportunities that are enunciated for us in our Declaration of Independence and our Bill of Rights and the Preamble to the Constitution, and making sure that those commitments, those words, don't ring hollow for people who may be disabled, but that it extends to all people regardless—regardless—of their status in society, either developmentally, mentally, physically or otherwise. And you have really done it. You are the ones who have been out there pushing for it in your local communities and in your States.

And so, having the last word, it is I who want to thank you for all you have done, and I get to applaud you now. [Applause.]

[Additional statements and material submitted for the record follow:]

PREPARED STATEMENT OF THE UNITED CEREBRAL PALSY ASSOCIATIONS, INC. ALLAN I BERGMAN, ON BEHALF OF

United Cerebral Palsy Associations, Inc. (UCPA) is pleased to submit comments on the Reauthorization of the Developmental Disabilities Assistance and Bill of rights Act. UCPA is a network of 182 affiliates which advocate for and/or provide services to individuals with cerebral palsy and other severe disabilities and their families.

Twenty years ago Congress recognized the need to expand the target population of the then Mental Retardation Facilities and Community Mental Health Centers Construction Act (P.L. 88-164 and P.L. 90-170) when it adopted the term developmental disabilities in 1970 in P.L. 91-517. In 1978, Congress took a further step by adopting the current functional definition of developmental disabilities in P.L. 95-602.

In 1987, UCPA provided testimony to this Subcommittee by Judy Hoyt, a parent of a young man with cerebral palsy who clearly meets the functional definition of developmental disabilities and who had benefitted little from the overarching principles of the Act in his home state of Massachusetts. Mrs. Hoyt stated that in the majority of the states the Developmental Disabilities Planning Councils were still perceived by many persons to do planning and advocacy primarily on behalf of persons with mental retardation rather than the full range of developmental disabilities attributable to physical impairments, mental impairments or a combination of physical and mental impairments.

As a result of her testimony and other materials presented to you, the Subcommittee took the lead in the 1986 amendments (P.L. 100-106) in developing a set of recommendations for each Developmental Disabilities Planning Council to follow in developing what is now commonly referred to as the 1990 reports. UCPA, on behalf of 700,000 persons with cerebral palsy and their families, is very appreciative of the Subcommittee members and its chairman, Senator Thomas Harkin, for the responsiveness and leadership demonstrated in these amendments including the addition of a definition of assistive technology within the Act.

As part of the technical assistance to the States in completing the required analyses for the 1990 reports, UCPA was awarded a subcontract from the National Association of Developmental Disabilities Councils to conduct a forum and provide a report on three critical policy issues in planning for a comprehensive service system for all persons with developmental disabilities and their families which would result in increased independence, productivity and community integration. A copy of that report, dated April 1989, which was disseminated widely, is attached to this testimony for the record as **Appendix A**.

THE 1990 REPORTS:

During the past few months, UCPA surveyed all of its affiliates on the process and outcomes of the Councils' 1990 report. Thirty-one affiliates from twenty-two states responded. Eleven of the twenty-two states reported that persons with disabilities other than mental retardation were well-represented in the consumer satisfaction survey. In only a few states did it appear that the primary respondents to the survey were persons with mental retardation. Thirteen of the twenty-two states reported that the overall report and responsiveness by the Council to persons with developmental disabilities attributable to physical impairments was good to excellent. On the other hand, six states reported the latter as fair, or poor, which is of considerable concern to UCPA.

RECOMMENDATIONS FOR REAUTHORIZATION

UCPA participated in the work of the Consortium for Citizens With Disabilities (CCD) and in general supports the CCD recommendations submitted to the Subcommittee on March 7, 1990.

The Developmental Disabilities Assistance and Bill of Rights Act consistently has represented the cutting edge and best practice for persons with developmental disabilities in this country and we encourage the Subcommittee to continue this trend in amendments to the Act this year so that the values embodied in the Act continue to provide a vision of the preferred future and the moral tone for this population.

UCPA recommends the following issues for the Subcommittee's consideration:

1. To amend and clarify the definition of family support, individual support and community support;

2. To revise the definition of assistive technology to be consistent with the definition in P.L. 100-407 and to link the critical role of assistive technology to the desired outcomes of independence, productivity and integration for thousands of persons with developmental disabilities;

3. To assure the inclusion of the recommendations of the Planning Councils within the 1990 reports as specific objectives and activities for subsequent years with the allocation of resources equitably distributed across all persons with developmental disabilities;

4. To require periodic reporting by the Councils, P&As and UAPs on the population(s) addressed through their activities and resource expenditures, with appropriate oversight by the Secretary, so that the fact that the Councils have spent over $7 million to promote supported employment can be reconciled with the recent reports from

the Department of Education and Virginia Commonwealth University that find that only 0.6 to 2.0 percent respectively of the persons receiving supported employment services in the country are persons with cerebral palsy;

5. To require that the core of training initiatives within the UAPs impact persons with the full range of developmental disabilities, are competency based and fully reflect value-driven, best practice approaches to service and support in the 90's;

6. To add positive behavior management and assistive technology as essential areas of the UAP core training program because of the critical roles these programs play in removing the barriers to independence, productivity and integration for persons with developmental disabilities ;

7. To assure that the Grants of National Significance for the collection of data on residential services, expenditures and employment, and require the collection of appropriate data on persons with developmental disabilities attributable to physical impairments, in addition to data on persons with a primary condition of mental retardation; and

8. To reauthorize the Act for no more than three years so that Congress can assure timely oversight of the implementation of the 1990 reports, the national data collection efforts, and continuing rapid changes in the field.

ADDITIONAL ISSUES FOR THE 1990'S:

During the Subcommittee's hearing on March 30, Chairman Harkin asked one of the witnesses to inform the Subcommittee on the major issues and trends that will be affecting the lives of persons with developmental disabilities and their families during the decade of the 90's. UCPA wishes to make the following statement in response to this question:

As the Subcommittee deliberates this reauthorization of the Developmental Disabilities Assistance and Bill of Rights Act, UCPA is confident that under the continued leadership of the Chairman, Senator Harkin, and the Ranking Member, Senator Durenberger, Congress will send the Americans with Disabilities Act to President Bush for his signature. How wonderful -- a declaration of the full civil rights of all persons with disabilities and a statement that discrimination, prejudice, exclusion, segregation, overprotective rules and policies, relegation to lesser services, and stereotypical assumptions will no longer be tolerated in our society and that the Nation must assure the proper goals of "equality of opportunity, full participation, independent living and economic self sufficiency" for all individuals with disabilities.

As Senator Harkin said in his opening statement on March 30, 1990, "This is an exciting and unprecedented opportunity for progress, and one we must take full advantage of." We at United Cerebral Palsy Associations, Inc., wholeheartedly agree.

The passage of the ADA and the reauthorization of the Developmental Disabilities Act represent a critical foundation for the 90's, however, for most people with the most severe developmental disabilities they represent the potential of another laudatory set of words and hollow promises. Without restructuring federal financing to states for programs and services to persons with developmental disabilities, Medicaid funding for the ICF/MR program will continue to represent over 6.5 percent of all federal funds sent to the states for such efforts.

As former Senator Lowell Weicker stated in his testimony of March 22, 1988, to the Senate Finance Committee, "As lawmakers, it is our responsibility to enact legislation consistent with constitutional guarantees of equal rights. Yet the Medicaid program as it relates to the disabled can still be summed up in the two words 'segregation' and 'inequality', for it is based on outmoded stereotypes of people with disabilities."

In FY '88, according to the data collected by Dr. David Braddock and his colleagues at the University of Illinois UAP and with funding from a Grant of National Significance, the federal government spent $3.38 billion on the ICF/MR program (84 percent for facilities for 16 or more persons), $500 million for persons with developmental disabilities in nursing homes, and only $248 million (reported as $487 million in Fy '90 by the National Association of State Mental Retardation Program Directors) on Home and Community Based waiver services.

1. UCPA encourages the Subcommittee to endorse Senator John Chafee's S.384, The Medicaid Home & Community Quality Services Act, and to urge Senator Lloyd Bentsen, Chairman of the Senate Finance Committee, and all of the committee's members to mark up and send to the floor this essential piece of financing legislation to enable people with developmental disabilities to have the opportunity to reach their dreams and achieve the vision promised within ADA and the DD Act.

2. In spite of 15 years of experience under the provisions of P.L. 94-142, the Education for All Handicapped Children Act of 1975, the overall data reported by the Department of Education indicates that there has been almost no change in the percentage of children with disabilities who received

their educational services in segregated settings. UCPA urges the Subcommittee to consider these findings in its conference committee deliberations and report with the House on the 1990 reauthorization of EHA. Moreover, UCPA urges the Subcommittee to assure an essential role for assistive technology as a related service in a child's IEP to remove the barriers to independence and participation in the mainstream.

3. In 1990 the Subcommittee will reauthorize the landmark legislation it enacted in 1986, P.L. 99-457, Part H. UCPA urges the Subcommittee to assure full funding at the bill's authorizing level for FY '91 in order to provide every possible fiscal incentive for states to adopt their program as an entitlement to guarantee all infants, toddlers with disabilities and their families the "Head Start" they need to assure a valued future of participation, inclusion, contribution and interdependence. Moreover, UCPA encourages the Subcommittee to monitor the Administration's interagency coordination efforts in light of the Medicaid EPSDT mandates effective April 1, 1990 and the new Maternal Child Health Title V Block Grant legislation enacted in OBRA '89 (P.L. 101-239).

4. The Rehabilitation Services Administration is currently receiving comments on changes in the regulations for the supported employment program which the Subcommittee created in 1986 (P.L. 99-506). UCPA urges the Subcommittee to monitor this process to assure that any changes in the regulations are consistent with Congressional intent and that supported employment becomes the vehicle for meaningful, integrated employment as intended rather than another barrier to employment for persons with developmental disabilities. UCPA's comments on the regulations are attached as **Appendix B**.

5. During the next few months the Senate and House conferees will be debating the final version of major child care legislation. To date, minimal provisions have been included for children with disabilities. UCPA urges the Subcommittee, under the principles embraced within the ADA and the DD Act, to work with the Senate conferees to assure the full inclusion of children with disabilities in the daycare provisions with a recognition of the specialized training needs and additional funding to assure opportunities for full inclusion and integration of children with disabilities and their families in generic day care.

6. In data recently reported by Dr. Jim Gallagher and his colleagues Dr. David Loder at the University of North Carolina, Chapel Hill, in assessing the personnel needs for implementation of P.L. 99-457, they state the following shortages:

1990	Projected by 2000
Occupational Therapy 7,000	11,000
Physical Therapy 3,000	28,000
Speech/Language Therapists 12,000	64,000

They further recommend the need to develop alternative methods of service delivery in order for infants, toddlers and preschoolers (N.B. as well as children and adults) to receive the benefits of these interventions. UCPA urges the Subcommittee to be cognizant of these personnel shortages and the need to assure appropriate legislative standards so that the highest desirable professional standards do not serve as an excuse for no services.

United Cerebral Palsy Associations, Inc. appreciates the opportunity to provide these comments. We commend the Subcommittee for their outstanding work to date and look forward to working with you on all of the above issues in order to implement the vision we all share for our citizens with developmental disabilities and their families.

Attachments

AIB:js

APPENDIX A

National Association of Developmental Disabilities Council report

(The report referred to is retained in the files of the subcommittee.)

Senator HARKIN. The subcommittee will stand in recess. Thank you.

[Whereupon, at 12:05 p.m., the subcommittee was adjourned.]

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